

Diabetes and its care — what do patients expect?

ANN-LOUISE KINMONTH

ELIZABETH MURPHY

THERESA MARTEAU

SUMMARY. A sample of 77% of the non-insulin dependent diabetics aged 30–70 years from two urban practices offering no structured diabetic care were interviewed. The 55 patients (mean age 60 years) were asked about their experiences and expectations of diabetes and the health professionals involved in their care. Twenty six patients attended the hospital diabetic clinic regularly but 13 patients received no review at all; 46 patients wanted their general practitioner to be involved in future care and only six wanted to continue with hospital review alone. Patients gave hospital doctors and general practitioners similar high ratings for knowledge of diabetes and its management but general practitioners and practice nurses were rated more highly for communication and accessibility. The aspect of care valued most was being given clear information about diabetic management.

Twenty two patients thought that diabetes would have a significant impact on their future health and 35 rated regular diabetic review as extremely important in keeping themselves healthy. Most patients felt it likely that they would have a high blood glucose level most of the time and develop diabetic complications. Little difference was found between the views of clinic attenders and non-attenders, and there was no evidence that non-attenders had actively rejected review.

These non-insulin dependent diabetics considered diabetes to be a serious disorder warranting regular care and expressed confidence in the primary care team's ability to provide such care.

Introduction

THE majority of non-insulin dependent diabetic patients depend on general practice for routine care and surveillance^{1,3} and considerable attention is being paid to improving that care.⁴ Central to such attempts is an understanding of patients' views as these may affect initial attendance at new schemes of care offered in general practice,⁵ and these views should be taken into account in planning services.⁶ There is, however, little information on the importance that non-insulin dependent diabetics attach to different aspects of diabetic care, the beliefs they hold about the ability of different health professionals to deliver care, or the effect that different experiences of health care have on these perceptions.

A survey has therefore been carried out among the non-insulin

dependent diabetics in two suburban practices as part of a study of introducing diabetic surveillance into general practice.⁷

Method

Patient sample

The patient sample was drawn from two suburban practices with a combined population of 14 957 and mean list size per general practitioner of 2000 patients. Neither practice had any policy for offering structured diabetic review within the practice. Over a six month period a diabetic register was compiled based upon repeat prescriptions and recall by receptionists and general practitioners. Of the 168 patients with diabetes who were identified, 112 were non-insulin dependent. The 71 non-insulin dependent diabetics who had been registered with the practices for more than one year and were aged between 30 and 70 years, were asked to take part in the study by letter and subsequent telephone call. Fifty five patients (77%) were interviewed.

Blood glucose control

A venous blood sample was obtained at a routine surgery visit from 51 of the 55 patients interviewed, for estimation of glycosylated haemoglobin (HbA_{1c}) level using Corning electrophoresis (normal range 5.2–7.3%).

Place of care and consultation rate

Following examination of their practice notes patients were categorized into one of three groups: those attending the hospital diabetic clinic at least once a year for review (clinic attenders), those receiving some care in general practice, and those receiving no regular care (non-attenders). The notes of non-attenders had no evidence of regular consultations to discuss diabetes over the previous two years either at hospital outpatient departments or in general practice.

The consultation rate was defined as the number of consultations recorded in the practice notes in the year in which the study took place (1985–86).

Questionnaire

A structured questionnaire was developed to elicit patients' preferences for future diabetic review. Respondents stated where they would like attend for regular review of their diabetes. They rated the performance of four professionals (hospital doctor, practice nurse, general practitioner or diabetic liaison sister) 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 of the aspects of care they valued most.

The perceived impact of diabetes and diabetic complications was explored using questions which drew upon the health belief model.⁸ The health belief model suggests that patients are more likely to follow a recommended treatment for a disease if they believe the disease is serious, that they are vulnerable to it and that the perceived benefits of undertaking the treatment outweigh the costs. Respondents were asked to state how much of what happened to their health in the future would be due to their diabetes (possible responses: much, little, do not know). They also rated the importance of regular diabetic review in keeping

A.-L. Kinmonth, MD, senior lecturer in primary medical care, University of Southampton; E. Murphy, MSc, social scientist, Department of Primary Medical Care, University of Southampton; T. Marteau, PhD, lecturer in health psychology, Royal Free Hospital, London.

© *Journal of the Royal College of General Practitioners*, 1989, 39, 324-327.

them healthy on a seven-point scale from 1 (not at all important) to 7 (extremely important).

Their perceptions of diabetic complications were then explored. Patients stated which of a range of health problems they were familiar with; these included items directly associated with, related to, or unrelated to, diabetes. Those patients who had heard of a condition rated its perceived severity and their sense of vulnerability to it on a scale from 1 (not at all serious/likely) to 6 (extremely serious/likely).

The questionnaire was piloted for comprehensibility among 10 non-insulin dependent diabetic patients outside the study. The revised questionnaire was administered by a single experienced interviewer in the patients' homes. The data were analysed by computer using the SPSSX package to test for the significance of differences between groups using the t-test statistic and for differences between proportions using the standard normal deviate. Significance levels are reported at the 5% level and below.

Results

Clinical characteristics of the sample

The clinical characteristics of the 55 patients interviewed are compared with those of non-responders in Table 1. The characteristics did not vary significantly at the 5% level.

Twenty six patients attended the hospital diabetic clinic regularly (attenders) and 13 patients did not attend anywhere for diabetic review (non-attenders). The remaining 16 patients received some care in general practice.

Preferred place of future review

Compared with the place of present review the patients showed a significant preference for the involvement of their general practitioner in future care (Table 2) — 38% of the 42 patients presently receiving medical review received care from their general practitioner compared with 85% of those wishing for review ($n=54$) (difference in proportions 47%; $P<0.001$; 95% confidence interval 28–66%). Moreover, 11 of the 13 non-attenders wanted diabetic review in the future, nine of them wanting general practitioner care alone.

Attitudes to health professionals and aspects of care

All 55 patients knew their general practitioner and 48 had met a hospital doctor for diabetic care. Thirty eight patients had met the practice nurse but only nine had met the diabetic liaison sister and she was therefore excluded from further analysis. Not all respondents answered for each professional on each aspect. However, analysis using those cases where respondents had

Table 2. Patients' preferences for future place of care by present care.

Present care	Future preference for care (number of patients)			
	Hospital diabetic clinic	General practice	Both	Other
Hospital diabetic clinic attenders ($n=26$)	5	11	9	1 ^a
Patients receiving some diabetic care in general practice ($n=16$)	1	11	4	0
Non-attenders ($n=13$)	0	9	2	2 ^b
All patients ($n=55$)	6	31	15	3

n = number of patients in group. ^aPreference for diabetic liaison nurse
^bOne declined future review, one did not mind where care was supplied.

answered for all professionals on a given aspect, gave similar results to those cases where the respondent had answered on all aspects for a given professional. The total data set is presented in Table 3.

Overall, the practice nurses and general practitioners scored more highly than the hospital doctors. The scores for the hospital doctors and general practitioners on the aspects directly concerned with diabetes were similar, but they differed significantly on items which concern communication, convenience and accessibility ($P<0.001$). The practice nurses also scored significantly more highly than hospital doctors on being easy to talk to ($P<0.01$), good at listening ($P<0.05$), punctual ($P<0.001$) and easy to get hold of ($P<0.001$).

Responses from non-attenders were comparable with those from hospital attenders, except that non-attenders rated the practice nurse as significantly more able to give clear information than did hospital attenders ($P<0.05$). Non-attenders tended to rate hospital doctors as more punctual than those who attended the hospital clinic, but the difference was not significant.

The most valued aspect of care was the ability to give clear information about diabetic management: the three professionals were given similar ratings for this aspect.

Importance of diabetes and diabetic check-ups

Twenty two respondents felt that much of what happened in the future to their health would be due to diabetes, while 22 felt that little would, and 11 did not know. Thirty five patients rated regular diabetic review as extremely important in keeping them

Table 1. Clinical characteristics of responders and non-responders to the interview, and attenders and non-attenders at diabetic review.

	Interview group			Diabetic review group		
	Responders ($n=55$)	Non-responders ($n=16$)	Total ($n=71$)	Attenders ($n=26$)	Non-attenders ($n=13$)	Total ($n=39$)
Mean age (years) \pm SD	60.2 \pm 7.7	58.9 \pm 6.8	59.9 \pm 7.5	60.3 \pm 6.4	58.5 \pm 12.2	59.7 \pm 8.6
Number (%) of women	30 (55)	6 (38)	36 (51)	12 (46)	5 (38)	17 (44)
Mean duration of diabetes (years) \pm SD	6.7 \pm 5.8	7.1 \pm 5.6	6.7 \pm 5.7	8.0 \pm 6.9	5.3 \pm 3.6	6.8 \pm 6.2
Number (%) receiving tablet treatment	44 (80)	9 (56)	53 (75)	22 (85)	10 (77)	32 (82)
Mean HbA _{1c} level (%) \pm SD	9.5 \pm 2.7	9.5 \pm 2.2	9.5 \pm 2.5	9.2 \pm 2.2	10.9 \pm 3.9	9.8 \pm 2.9
Mean number of consultations per year \pm SD	5.1 \pm 4.9	3.6 \pm 5.2	4.4 \pm 5.0	6.6 \pm 9.3	4.2 \pm 4.4	5.3 \pm 7.9

n = number of patients in group. SD = standard deviation. No statistically significant differences were found between responders and non-responders or between attenders and non-attenders.

Table 3. Patients' ratings^a of the practice nurse, hospital doctor and general practitioner for various aspects of care.

Aspects of care	Mean score \pm standard deviation			Number of patients selecting as most valued aspect ^b
	Hospital doctor (n = 48)	General practitioner (n = 55)	Practice nurse (n = 38)	
Knowledgeable about diabetes in general	1.6 \pm 0.5	1.5 \pm 0.6	1.4 \pm 0.7	6
Knowledgeable about your problems with diabetes	1.4 \pm 0.7	1.4 \pm 0.7	1.2 \pm 0.7	10
Able to give clear information about how to manage your diabetes	1.3 \pm 0.7	1.4 \pm 0.7	1.3 \pm 0.7	21
Easy to talk to	1.1 \pm 0.7	1.8 \pm 0.4	1.8 \pm 0.5	6
Good at listening	1.0 \pm 0.7	1.7 \pm 0.6	1.7 \pm 0.6	2
Punctual	0.7 \pm 0.8	1.5 \pm 0.6	1.8 \pm 0.5	0
Easy to get hold of when you need them	0.6 \pm 0.8	1.6 \pm 0.5	1.6 \pm 0.5	9

n = number of respondents who had met each professional. ^a Scores from 0 (not very good) to 2 (very good). ^b Data missing for one patient.

healthy. The mean score for the whole group was 5.9 (standard deviation 1.8), and was similar for attenders and non-attenders at diabetic review.

Views about diabetic complications

The majority of patients were familiar with all the problems they were asked to consider (Table 4). With the exception of stomach ulcer, the two problems exclusively associated with diabetes (high blood glucose level and diabetic complications) were those that most patients expressed no knowledge of. This lack of knowledge was equally common among attenders and non-attenders at diabetic review.

Most of the items relating directly to or associated with diabetes were rated as very serious indeed, on a level with lung cancer. Only foot problems, high blood pressure and heart trouble were rated as less serious, and on a level with arthritis, bronchitis and stomach ulcers. All the respondents knew that smoking more than five cigarettes per day was a health risk and the mean rating of severity was 5.0 ± 1.4 . The majority of patients felt it was likely or very likely that they would have a high blood glucose level most of the time (n = 36) and develop diabetic complications (n = 33). Although there was a tendency for attenders at diabetic review to estimate the range of problems as more serious than non-attenders these differences only reached statistical significance for gangrene ($P < 0.05$). Responses to the questions on vulnerability were similar for attenders and non-attenders.

Discussion

These results show that non-insulin dependent patients from practices offering no structured diabetic care, are willing to receive such care, and from the primary care team rather than from hospital outpatient departments. This is despite the fact that the majority of patients under regular review were attending the hospital, and a considerable minority were receiving no regular diabetic care at all.

Patients often seem to be satisfied with whatever service they currently receive,⁹ but in this sample the majority of the 26 patients under review in the hospital diabetic clinic wanted general practitioner involvement in future care with only five patients opting to continue with hospital care alone. In contrast, only one patient out of 16 currently receiving care from general practice alone preferred to change to the hospital diabetic clinic and the majority of the 13 patients receiving no review wished to obtain follow up in general practice alone. These results suggest that there is considerable consumer support for the development of general practice based review of patients with non-insulin dependent diabetes. However, this choice of follow-up

does not seem to stem from a general underestimate among responders either of the potential impact of diabetes on health or of the importance of skilled help in minimizing this.

The majority of responders had heard of the range of diabetic complications and were somewhat pessimistic about the effect of diabetes on their future health. They expected to have a high blood glucose level most of the time, and felt vulnerable to diabetic complications. Against this background, more than half the patients considered diabetic check-ups to be extremely important in maintaining health. Moreover, it seems likely that they saw these check-ups as an active, health seeking activity of their own rather than a passive doctor-centred assessment, since the aspect of care chosen by the majority of responders as most valuable to them was the ability of professionals to give clear information about how diabetics might best manage their own care.

Table 4. Patients' views about health problems.

Health problem	Number of respondents		Mean score ^a \pm standard deviation	
	Unfamiliar with problem	Familiar with problem	Severity ^b	Personal vulnerability ^c
<i>Directly related to diabetes</i>				
High blood glucose level most of the time	8	47	5.2 \pm 1.0	4.2 \pm 1.1
Diabetic complications	8	47	5.1 \pm 1.0	4.0 \pm 1.1
Gangrene	4	51	5.7 \pm 0.7	1.9 \pm 1.1
Foot problems	6	49	4.4 \pm 1.4	3.1 \pm 1.6
Failing eyesight	2	53	5.1 \pm 1.2	4.1 \pm 1.4
<i>Associated with diabetes</i>				
Heart trouble	3	52	4.7 \pm 1.1	4.0 \pm 1.3
Stroke	3	52	5.1 \pm 1.1	3.3 \pm 1.5
High blood pressure	2	53	3.5 \pm 1.4	4.4 \pm 1.9
<i>Unrelated to or unassociated with diabetes</i>				
Lung cancer	1	54	5.6 \pm 1.0	2.3 \pm 1.3
Arthritis	1	54	4.6 \pm 1.3	3.6 \pm 1.7
Bronchitis	3	52	3.7 \pm 1.3	3.3 \pm 1.9
Stomach ulcer	10	45	3.8 \pm 1.2	2.1 \pm 1.5
Mouth ulcers	0	55	1.5 \pm 0.8	2.3 \pm 1.4

^a Mean score among those respondents who were familiar with the problem.

^b Scores from 1 (not at all serious) to 6 (extremely serious). ^c Scores from 1 (not at all likely) to 6 (extremely likely).

The patients' choice of professional for follow-up seems to reflect their confidence in the knowledge and skills of their general practitioner, rather than a belief that diabetes did not warrant special care. General practitioners and hospital doctors were thus given similar scores on the aspects of care related to knowledge about diabetic management. When aspects of care relating to communication and accessibility are considered, patients clearly rate primary care higher than secondary care. A preference for primary care has been reported before,^{2,9} but it has not previously been linked to patients' views of the significance of their disorder, their desire for structured diabetic care, and the value they attach to discussion of diabetic management with a knowledgeable professional.

This study also documents the emergence of practice nurses as valued members of the diabetes primary care team. The practice nurse achieved similar ratings to the general practitioner across all aspects of care, scoring quite well on knowledge about diabetes and provision of information and very well on accessibility, punctuality and general communication skills. Despite the presence in the district of a competent diabetes liaison sister, too few of the sample had met her to rate her abilities in care. These findings underline the difficulties for one specialist liaison sister of supporting face-to-face care of non-insulin dependent diabetes in a large district, and they point to the increasing importance of providing adequate training to the more accessible primary care nursing staff.^{10,11}

Any comparison of the perceptions of those who attended and those who did not attend diabetic review is limited by the small numbers in this study. However, there was evidence that the non-attenders would welcome diabetic review, with only one declining future review. Moreover, non-attenders recognized diabetic complications and felt as vulnerable to them as did attenders.

Reasons for non-attendance for preventive care and surveillance are of growing interest^{12,13} and future studies among patients with chronic disease should define their groups carefully; in practices without recall systems, a major reason for non-attendance may be lack of organization rather than patient choice. This study addressed the expectations of patients rather than the ability of primary care to deliver care, but the results provide motivation for primary care professionals and their practices to offer more effective diabetic surveillance.¹⁴

References

1. Yudkin JS, Boucher BJ, Schopflin KF, *et al.* The quality of diabetic care in a London health district. *J Epidemiol Community Health* 1980; **34**: 277-280.
2. Dornan C, Fowler G, Mann JI, *et al.* A community study of diabetes in Oxfordshire. *J R Coll Gen Pract* 1983; **33**: 151-155.
3. Burrows PJ, Gray PJ, Kinmonth A-L, *et al.* Who cares for the patient with diabetes? Presentation and follow-up in seven Southampton practices. *J R Coll Gen Pract* 1987; **37**: 65-69.
4. Gibbins RL, Saunders J. How to develop diabetic care in general practice. *Br Med J* 1988; **297**: 187-189.
5. Wilkes E, Lawton EE. The diabetic, the hospital and primary care. *J R Coll Gen Pract* 1980; **30**: 199-206.
6. Secretaries of State for Social Services, Wales, Northern Ireland and Scotland. *Primary health care: an agenda for discussion (Cmd 9771)*. London: HMSO, 1986.
7. Callaway P, Kinmonth A-L, Leatherdale B. Developing a district diabetic service: a team approach. *Diabetic Medicine/Innovative Care Suppl* 1988; **5**: 681-692.
8. Rosenstock I. The health belief model and preventive health behaviour. *Health Educ Monogr* 1974; **2**: 354-386.
9. Cartwright A. *Patients and their doctors: a study of general practice*. London: Routledge and Kegan Paul, 1967.
10. Reading S. Developing the role of the practice nurse in diabetic care. *Practitioner* 1987; **231**: 1559-1562.
11. Hart JT. Practice nurses: an under used resource. *Br Med J* 1985; **290**: 1162.

12. Hammersley MS, Holland MR, Walford S, Thorn PA. What happens to defaulters from a diabetic clinic? *Br Med J* 1985; **291**: 1330-1332.
13. Pill R, Stott N. Invitation to attend a health check in a general practice setting: the views of a cohort of non-attenders. *J R Coll Gen Pract* 1988; **38**: 57-60.
14. Hayes TM, Harries J. Randomised controlled trial of routine hospital clinic versus routine general practice care for type II diabetics. *Br Med J* 1984; **289**: 728-730.

Acknowledgements

We gratefully acknowledge the work of Mrs M. Dolman in administering the interviews, of Mrs J. MacKean in providing statistical advice and Mrs J. Gibson in typing the manuscript. Grants were received from the Scientific Foundation Board of the Royal College of General Practitioners and from the Nuffield Provincial Hospitals Trust.

Address for correspondence

Dr Ann-Louise Kinmonth, Alderbrook Health Centre, Alderbrook Close, Southampton SO1 6ST.

RCGP

Scientific
Foundation
Board



RESEARCH FUNDING

Applications are now being received for grants for research in or relating to general medical practice, for consideration at the November 1989 meeting of the Scientific Foundation Board. In addition to its general fund

the Board also administers specific funds including the Windebank Fund for specific research into diabetes.

The Scientific Foundation Board's definition of research is catholic and includes educational research, observational as well as experimental studies, and accepts the methodologies of social science as valid. It is not in a position to fund educational activities.

If the study involves any intervention or raises issues of confidentiality it is wise to obtain advance approval from an appropriate research ethics committee otherwise a decision to award a grant may be conditional upon such approval.

Studies which do not, in the opinion of the Board, offer a reasonable chance of answering the question posed will be rejected. It may sometimes be useful to seek expert advice on protocol design before submitting an application.

Care should be taken to ensure that costs are accurately forecast and that matters such as inflation and salary increases are included.

The annual sum of money available is not large by absolute standards and grant applications for sums in excess of £15 000 for any one year are unlikely to be considered.

Application forms are obtainable from the Secretary of the Board at: The Clinical and Research Division, 14 Princes Gate, London SW7 1PU. The closing date for receipt of completed applications is 30 September 1989; any forms received after that date will, unfortunately, be ineligible for consideration.