

Older people's experiences of diabetes care

Stephen Abbott and Caroline Gunnell

ARTICLE POINTS

- 1 Older people were asked about their experiences of diabetes care.
- 2 Most were actively engaged in basic self-care.
- 3 Most had only a partial and rudimentary knowledge of diabetes.
- 4 Most self-care seems to reflect compliance rather than empowerment.
- 5 Some older people may wish not to be actively involved in decisions about their care.

KEY WORDS

- Self-care
- Older patients
- Informal support
- Professional support
- Education

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Introduction

Though self-care has a crucial role to play in diabetes management, as is clear from the National Service Framework for Diabetes (Department of Health, 2001), this raises particular issues for older people, who may find self-care more of a burden because of increasing frailty or ill-health. This paper reports the findings of a research study which asked older people about their experiences of diabetes care. At the same time, the research project was designed to build the research and development capacity of practice nurses by using volunteers as interviewers (Abbott and Gunnell, 2004).

Surprisingly little research has been done on diabetes management from the perspective of patients and their relatives, and older people in particular. The research study outlined in this paper explored older patients' experience of diabetes services and self-care.

Data were gathered by structured interviews. These included both yes/no and tick-box questions along with open-ended questions. Interviews were recorded for accuracy.

Participating nurses recruited patients to the study as and when they were able to. It is not, therefore, a representative sample, but this is acceptable in an exploratory study which seeks not to make generalisations but to identify key themes.

Data were entered into a Microsoft Access database, and framework analysis was carried out (Ritchie and Spencer, 1994).

Results

Fifty-eight interviews were carried out by nine researchers who were trained to give structured interviews: seven practice nurses, one community DSN and one DSN in an outpatients clinic.

Of the 58 interviews, four have been excluded from this analysis because the data recorded were so brief and factual that they could not be described as qualitative data.

The profile of those interviewed is set out in Table 1. Most were white British, although six were of south Asian origin. Fifteen had had diabetes for over 10 years (about 40 years in

two cases). Sixteen respondents took insulin.

The views reported here were evident across the range of respondents: no views were voiced exclusively by any particular group of patients (e.g. men or women; older or younger; more or less recent onset). Not surprisingly, older and more infirm people more commonly voiced a preference for a more passive role in their care, but this was by no means always the case.

Self-care tasks undertaken

Almost everyone interviewed took some active role in the management of their diabetes. Almost all those who had been prescribed oral medication looked after their tablets themselves, except for those in residential care, and two disabled men whose wives took charge of medication. Those who needed insulin administered it themselves.

Many respondents also tested themselves. Urine and glucose tests were the most common, with a handful also taking their own blood pressure (usually with equipment which they had bought themselves). A small number had chosen not to test themselves because they felt that to do so would make them anxious.

In all of these cases, respondents did not generally report finding self-care difficult, as the requisite procedures were easily explained, whether this had been done orally by healthcare staff or in written form (instructions, e.t.c.).

Much more troublesome was the management of diet. Almost all respondents

said that they should avoid sugar, and some said that they should avoid fat or oil. Most reported that they had seen a dietitian at some point, often when first diagnosed, but some were uncertain about what to do:

'I need someone to make sure my food is balanced, because I could be wrong.' (F72)

(Note: Individual respondents are referred to by gender and age, e.g. F75, M66). Many admitted that they occasionally flouted the rules ('Every now and again I have a treat.' [M69]) and a few said that they disregarded the rules altogether: 'I eat what I want'.

Informal support

It was not uncommon for family or occasionally friends to be involved. A number of men said that their wives were very involved in deciding what they should eat, for example. A man aged 87 recognised his wife's support by saying 'my wife is my care plan'. However, some respondents or their carers clearly found it difficult to cater for diabetes and non-diabetes needs at the same time:

'My wife still likes to see an empty plate... it's hard to get her to give me small helpings.' (M72)

A number spoke of their families' vigilance about diet:

'If my children see me with a piece of cake... it gets chucked in the bin.' (F71)

Professional support

Not surprisingly, most expressed satisfaction with the healthcare they received, as is usual with older patients, but a significant minority identified deficits. A number of people wished to be seen by professionals more often:

'I need more regular visits from nurse to keep me in line.' (M65)

Several of those who were housebound regretted the absence of regular home visits. A few complained that healthcare professionals (usually GPs and hospital doctors) gave too little time for each consultation, so that the patient felt rushed.

There were a few complaints about not being able to make an appointment in the near future (GP, eye specialist) and about lack of continuity of professional care (optometry, hospital medicine). There was also particular

dissatisfaction with chiropody services.

Respondents were asked whether they had a personal care plan or patient-held record. Only one person reported having a care plan, although one person answered: 'Yes, but not written'. One had a social care plan. A few said that they had a patient-held record.

Understanding and knowledge

Various levels of understanding and knowledge were articulated. Almost everyone knew that various aspects of their care were linked to diabetes: the need to reduce sugar intake, the need to test blood glucose and/or urine, the need to have eyes and feet checked. This knowledge was not apparently accompanied by any real understanding of diabetes, e.g. the nature of the link between diabetes and feet or eyes.

While some made it clear that they had not asked for information, some people expressed the wish for more knowledge.

'I've never asked anyone about diabetes, but I'd like to know.' (F91, in residential care)

One explained that diabetes did not impact on her life sufficiently to warrant seeking more information:

'If I had it really bad... I might be interested.' (F80, housebound)

One woman (aged 80) indicated that simply receiving information did not guarantee knowledge and understanding:

'I've picked up information as I've gone along, but still I feel I'm quite ignorant.'

Partly, this might be because, as she went on

PAGE POINTS

1 Whilst respondents did not generally report finding self-care difficult, diet management was considered more troublesome.

2 It was not uncommon for family or occasionally friends to be involved in caring for elderly patients with diabetes.

3 Most respondents expressed satisfaction with professional care, but a minority identified deficiencies.

4 Various levels of understanding were articulated by the respondents. Some expressed a wish for more knowledge.

Table 1. Profile of respondents

Age	Male	Female
65-69	10	5
70-74	5	8 (1 housebound)
75-79	2 (1 housebound)	6 (2 housebound)
80-84	7 (2 housebound*, 1 in residential care)	7 (5 housebound, 1 in residential care)
85-89	1	1 (housebound)
90+	1 (in residential care)	1 (in residential care)
Total	26 (3 housebound, 2 in residential care)	28 (9 housebound, 2 in residential care)

*In one case, the patient's wife answered on behalf of her husband.

PAGE POINTS

- 1 Most respondents seemed to be satisfied with their level of self-care.
- 2 The importance of providing continued, adequate information to patients is a key theme.

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Pooley CG, Gerrard C, Hollis S, Morton S, Astbury J (2001) 'Oh it's a wonderful practice... you can talk to them': a qualitative study of patients' and health professionals' views on the management of type 2 diabetes. *Health and Social Care in the Community* 9: 318–26

Ritchie J, Spencer L (1994) *Qualitative data analysis for applied policy research*. In: Bryman A, Burgess RG (eds.) *Analyzing Qualitative Data*, pp.173–194. Routledge, London.

Waterworth S, Luker K (1990) Reluctant collaborators: do patients want to be involved in decisions concerning care? *Journal of Advanced Nursing* 15: 971–76

to point out, information was frightening. Another felt that:

'Healthcare professionals need to use simpler words and explanations when discussing diabetes, to make it easier for patients to understand' (M67).

One said that, for these reasons, health education delivered orally was preferable: 'talking about it helps the most' (F71).

Quite a lot of respondents mentioned using multiple information sources, such as health professionals, Diabetes UK, newspapers. Several of the nurse interviewers were struck by the lack of knowledge described by many of their patients, to whom they had themselves given more information about diabetes than had apparently been retained.

Taking responsibility

Most respondents seemed to be satisfied with the level of self-care they were undertaking, and to see healthcare professionals as a necessary back-up. However, it seemed that in most cases, respondents saw themselves as complying with professional instructions rather than taking individual responsibility. Several used the phrase 'I do what I'm told'.

Some respondents did describe having taken a positive choice:

'I like being in control of my life and my diabetes management.' (M69)

By contrast, a man who had had diabetes for many years confessed:

'I'd leave everything to [other people] if I could.' (M80, in residential care)

There was an interesting example of how patient autonomy may go against health professionals' advice in a man (aged 83) who deliberately used smoking as a 'treatment' when he could not sleep, calming him and helping with feelings of loneliness.

Discussion

Our data is largely consistent with the existing literature on the patient experience of diabetes care. The importance of information, its adequacy and continued availability over time, is a key theme: Hiscock et al (2001) found that the information-giving

process needs to be ongoing and interactive, and Hares et al (1992) also found that information given in person is particularly valued by some patients. Pooley et al (2001) found that some patients who are underinformed admitted that they do not ask for information: in some cases, because they preferred not to know 'too much'. It would be interesting to assess in more detail the relationships between people's appetite for knowledge, their actual knowledge, and their satisfaction with knowledge levels.

The preference for more frequent review reported by Hiscock et al (2001) is consistent with our finding that some patients felt undersupported, and the low numbers of patients who reported having a care plan reflects other studies (Abbott et al, 2001). Interviewers reported that they did not need to make radical changes to treatment and management regimens as a result of the interviews, so patient dissatisfactions probably reflect different expectations of what the appropriate level of care is. However, the NSF (DoH, 2001) indicates that patients should have a care plan.

Although most of those interviewed were actively and regularly engaged in basic self-care tasks, they generally had only a limited understanding of the disease and its effects. Generally, self-care seems to be done in a spirit of compliance with the instructions of healthcare professionals, rather than as part of a proactive desire to 'control one's destiny'.

How should services respond to patients who prefer not to be involved in their care? Patients may be 'reluctant collaborators' (Waterworth and Luker, 1990), with a range of reasons for preferring not to participate (Biley, 1992). On the other hand, it is reasonable to assume that most older patients will be more used to clinician-directed care than to sharing decision-making (Florin and Coulter, 2001). There is clearly scope, therefore, for nurses to give older patients the opportunity to experience a more shared consultation style which patients can then accept or reject. ■

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