

Research paper

'A one-to-one thing is better than a thousand books': views and understanding of older people with diabetes

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ABSTRACT

Background Specific aspects of care have been identified as important in order to provide high-quality care for patients with diabetes, including the need for patients to understand their condition. Little research has specifically explored the views and understanding of older people with diabetes in primary care.

Aims To explore views on quality of diabetes care and to gauge patients' understanding of their condition in order to identify areas for improvement in care.

Methods During August and September 2012, 13 semi-structured interviews were held with people with diabetes aged over 75 years, recruited from an inner-city general practice. The interviews focused on three areas: (1) their understanding of diabetes, (2) their views on the information they had received, and (3) their views on the quality of their care. The qualitative data were analysed using N-Vivo and techniques derived from framework analysis.

Results A basic understanding of diabetes was shared among the responders, but certain gaps

were identified, notably misunderstandings regarding hypoglycaemia and diabetic coma. Information was valued most if given in person; written information may not be impactful. Educational input attenuated over time and patients did not actively seek updating. Personal care was appreciated, but many patients expressed a desire to be kept better informed about their treatment.

Conclusions Older people with diabetes wish to be involved in their care. Healthcare providers should regularly assess patients' knowledge in order to resolve potentially harmful misunderstandings. Explanations should be detailed and repeated, and sources of information need to be user-friendly as appropriate to this age group. Nurse-led, more continuous care was highly acceptable.

Keywords: attitudes, general practice, older people, primary care, quality, type 2 diabetes mellitus

How this fits in with quality in primary care

What do we know?

Diabetes is placing growing demands on health services. Various bodies have drawn up standards of care for people with diabetes. Increasing numbers of people are surviving into old age with the disease. However, little is known specifically about the priorities and views of this group on their care.

What does this paper add?

This study indicates the need to improve diabetes service in some key areas. Although many older patients may not always wish to be actively involved in decision making, it is important to keep them informed. Healthcare providers should regularly assess patients' knowledge in order to resolve any potentially harmful misunderstandings. Education initiatives such as DESMOND are likely to be more effective if delivered in an ongoing way. Sources of information need to be user-friendly as appropriate to this age group. Nurse-led care with an emphasis on continuity and emotional support is well accepted in this age group.

Introduction

Type 2 diabetes mellitus is a disease associated with ageing. The prevalence of type 2 diabetes in the UK in people aged 75 years or over is 13.5% for men and 10.6% for women.¹ The National Service Framework (NSF) for diabetes was introduced in 2001 to address the needs of people with diabetes in the UK. It promoted the 'empowerment' of patients and emphasised the need to provide them with the 'knowledge, skills and motivation' to manage their condition effectively.² Education programmes, such as Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND), have been launched nationwide in order to equip patients with information about diabetes and how they can manage it.³ The standard DESMOND programme involves 6 hours of structured self-management group education delivered over one day or two half-days in a local centre.³

Diabetes UK has described 15 'healthcare essentials' which it describes as 'the minimum standard of care that people with diabetes need to help manage their condition'.⁴ Of these, 12 are quantitatively verifiable (e.g. the recording of annual blood pressure measurements). They also identified the need for patient education, individualised care plans and emotional support. The NSF for Older People also highlights the need for individualised care specifically for older people.⁵ The delivery of these three areas is less easily monitored. Other studies have demonstrated the significance of continuity of care and ease of access for patients with chronic conditions managed in primary care.⁶⁻⁹ Patients' perceptions of the quality of their care in these areas are difficult to ascertain without collecting patient feedback.

Research has shown the value of qualitative studies in identifying issues faced by particular population groups.^{10,11} Many qualitative studies have investigated the views of people with diabetes¹¹⁻¹³ which have raised issues such as a lack of collaborative care,¹¹ gaps in patient knowledge¹³ and the lack of follow-up after certain interventions.¹⁴ One study into older people's views emphasised the need for individualised care.¹⁵ However, no studies were found which specifically examined older people's opinions of primary care in the UK.

The aim of this study was to investigate older people's views of the care they receive for their diabetes. We focused on those areas of care quality highlighted by Diabetes UK. In addition to studying people's opinions on quality of care in general, we specifically looked at the need for education. Older people were asked their opinion about the information they had received and we attempted to gauge its effectiveness by assessing their understanding of diabetes.

Methods

Interviewees were recruited from an inner-city general practice serving a predominantly deprived population in Luton. They were aged over 75 years with a diagnosis of type 2 diabetes and were selected to ensure diversity in age, sex, ethnicity and severity of their disease. Patients with dementia were excluded.

Patients were formally consented and interviewed at home. Semi-structured interviews were conducted, recorded and subsequently transcribed. The interviews explored their views on the quality of care and the information they had received, and their understanding of diabetes. (The questionnaire is reproduced in the Appendix.) Thirteen patients were interviewed and saturation was reached.

N-Vivo v. 9.0 computer software was used for coding and analysis. Data were interpreted using techniques derived from framework analysis.^{16,17} The researchers coded early transcripts separately, with good conceptual agreement on the emergent codes and thematic framework. We grouped codes together under themes and sub-themes, actively sought examples that did not fit with codes, and revisited transcripts to refine and validate the findings. The coding frame eventually covered all areas of data and corresponded to themes included in the interview schedule plus some emergent, unanticipated issues. Quotations from a wide range of interviewees have been selected to illustrate themes.

Results

Responses were analysed within three main themes relating to patient understanding, information and quality of care.

Patient understanding

The people interviewed were specifically asked about their understanding of their condition and its complications. In addition, sub-themes emerged regarding their attitude to the condition, their understanding of diet and fears of coma.

All but one patient demonstrated a basic framework of understanding regarding the nature of their disease. The majority of patients offered responses such as 'too much sugar in the blood' (Interviewee 7), and four patients mentioned the pancreas and its failure to produce insulin. However, most patients expressed in some form uncertainty, or said that they had forgotten aspects of what the disease is.

Responses about the long-term complications of diabetes were also generally well-informed. Eight patients referred to specific organs affected by diabetes (kidneys and eyes were most frequently mentioned), and other patients used phrases such as 'it could damage my system' (Interviewee 9). Only one patient said that they were not aware of what could happen with poor control.

Among the respondents there was a wide range of attitudes about the severity and importance of diabetes. Some patients were surprisingly relaxed about their condition:

I don't really class myself as a diabetic, let's put it that way. Although I've got it, I know. (Interviewee 3)

Of course, type 2 is not all that serious apparently as far as I know. (Interviewee 6)

Their approach to following a diet designed for people with diabetes was similarly relaxed:

As I say, I don't really stick strictly to a diet as I should do. I just eat as and when I feel like eating whatever I feel like eating. It doesn't really affect me so ... (Interviewee 3)

However, other patients clearly took diabetes very seriously and appeared frightened about what could happen:

I was terrified ... diabetes could mess up your whole life. (Interviewee 9)

... it destroys all the organs in the body. (Interviewee 11)

These patients expressed a desire to control their diet more strictly:

You have to stay careful all the time, you not eat this, you eat that, all of this thing you know. (Interviewee 11)

Six patients discussed their fears of 'diabetic coma' and this was related to what they thought would happen if their sugar levels became too high, despite all of them having relatively well-controlled type 2 diabetes. One lady (with limited spoken English) described her fears as: 'Can go on the floor if you stay very high' (Interviewee 11). Interestingly, although these patients had expressed uncertainty about their knowledge of diabetes in general, they expressed their perception of being at risk of coma confidently and with little doubt:

Oh yea, you go into a coma, a diabetic coma. (Interviewee 6)

The patients taking insulin or oral hypoglycaemic agents (e.g. sulphonylureas) were asked about their knowledge of hypoglycaemia (explained as 'when your sugars go very low'). The responses varied, but only two of the eight patients at risk showed a clear understanding of what symptoms to look out for, and what to do if those symptoms occurred. Some patients confused low and high blood sugars. For example, one patient on insulin described quite clearly

an episode of giddiness followed by a fall, which was improved when a nurse gave her some sugar. She continued:

I think they must have been high [sugars], I don't think it went low ... I really understand most of what I should be doing, there's really not a lot I don't understand. (Interviewee 12)

Information

Interviewees were asked for their opinions on the quantity of information, its mechanism of delivery, and they were specifically asked about DESMOND. From the interviews sub-themes emerged regarding the practical limitations of leaflets and the internet, follow-up information post diagnosis, and the issue of remembering or forgetting information.

Respondents were satisfied with the amount and quality of information given about diabetes. However, there were uncertainties and misunderstandings, as illustrated above. Although patients were happy with the information, it may not necessarily have been effective at educating the patient:

They explained quite a bit. Of course, you don't take a lot of notice of it. (Interviewee 6)

People valued face-to-face explanations highly, with mixed views on written information:

They gave us a whole bunch of literature to read but that's not the same thing as talking to people ... a one-to-one thing is better than a thousand books. (Interviewee 8)

I have got leaflets and booklets and things on it, which I don't really look at to be honest. (Interviewee 10)

One patient also highlighted the problem with written information for those with eyesight difficulties; more common in an older age group. Another patient mentioned that the only information she had was from over 20 years ago when she was first diagnosed.

DESMOND has been available for several years but no patient recognised the name of the programme, although five of the 13 had attended a group teaching session. Overall, people were positive about education sessions:

My memory of those early days were the efforts that were made to educate us. And I really appreciated it because I do the cooking and I hadn't got a clue what to do. (Interviewee 13)

When discussing information, it consistently emerged that patients were given a lot of information initially upon being diagnosed. This then tapered, leaving many patients feeling they were 'left alone to get on with it of my own devices' (Interviewee 2). Patients also frequently acknowledged that they had forgotten information:

This original diabetes seminar was just a one-time thing ... I don't remember too much what they said there and I think there should be kind of a follow-up on that. (Interviewee 8)

Quality of care

The interview asked open questions regarding care quality. Also, accessibility, continuity of care and individualised care were specifically explored. The sub-themes of frequency and content of appointments, humaneness, self-checking and issues with equipment emerged.

The majority of patients stated continuity was important to them and achievable in practice. However, nine patients mentioned that they had to wait a long while in order to see their preferred doctor. Nurse-led care was highly praised and appreciated by all who mentioned it (10 interviewees), particularly regarding accessibility:

That matron service helps a lot ... with the doctors it's mostly appointments but with them they come any time. (Interviewee 6)

It became very apparent from the interviews that what most people valued about their care was the person-centred element. When asked about the positive aspects of their care, the word 'kind' was mentioned more than any other adjective (five times). 'Genuine' and 'understanding' were also used to describe those involved. However, in response to questions regarding emotional support, the majority of interviewees (10) were negative or non-committal: 'I suppose so' (Interviewee 4), 'I couldn't say that I don't' (Interviewee 9). Only one patient replied positively: 'We do from [nurse name], she's all support' (Interviewee 13).

Ten of 13 people interviewed found the concept of being involved in their own care confusing. These patients expressed views in favour of a paternalistic approach to their treatment:

I don't say any opinion, because you know better than me. Don't you? (Interviewee 11)

They just said 'you take these' and that's it. And I take them. That's it. (laughs) (Interviewee 5)

However, it emerged that some patients felt detached from their care:

But what can you do? You have to rely on the doctors to keep checking on you. I got a thing to check the glucose level, but it don't mean a lot to you ... so you don't know what's going on really. (Interviewee 6)

Three patients expressed similar views about having home blood-monitoring kits. They had all bought their own because they 'wanted to know' (Interviewee 8), yet 'didn't know what to do with the results anyhow' (Interviewee 8).

As part of our questionnaire, we briefly explained the idea of performance-related pay and the Quality and Outcomes Framework in relation to diabetes management (using the example of targets for HbA1c). The respondents had mixed views on the principle:

It's a good idea, it gives them an incentive to help you, doesn't it? Good idea, yea. If they can get more money they're going to do more about it, aren't they, to keep it down (blood sugars). (Interviewee 6)

Rubbish – because the doctor cannot control it. He can advise you, give you bits of paper ... I don't mind a doctor having a bonus, I'm not saying that, but it's too much down to a stupid patient. (Interviewee 4)

None of the people interviewed had ever heard of performance-related pay for doctors, and most appeared surprised that it was in place.

Discussion

This was a small study, conducted in a single practice, and may not fully reflect opinions of people with diabetes nationwide. However, it raised important issues for those striving to improve services for people living with diabetes. No other studies have looked specifically at older people's views and understanding in the context of primary care in the UK.

This study reinforces existing research suggesting that the standards of patient empowerment set by the NSF and Diabetes UK are not being consistently met.^{18,19} Although the patients we spoke to were very positive about the personable nature of the care they received, most did not equate this to receiving emotional support. The idea of an individualised care plan was not generally well-received with the patients; many appeared reluctant to play an active role in decision making regarding their diabetes, which is consistent with other studies involving older patients.^{20,21} However, they did express a desire to be kept fully aware. They were particularly keen to have tests explained to them, and they wanted to know what the results meant in relation to their control of their condition. Forming an individualised care plan for each patient should consist of assessing how much each patient would like to be involved and informing them accordingly.

One of the principal aims of this study was to evaluate patients' understanding of diabetes in order to investigate the effectiveness of the education they had received. The older people questioned had a simplified view of diabetes, but generally some understanding of the scientific basis of their condition and its potential consequences. However, there were some key areas of consistent misunderstanding, principally

Box 1**Implications for health professionals**

- Although many older patients may not wish to be actively involved in decision making, it is important to keep them informed and involved.
- Healthcare providers should actively assess patients' knowledge in order to resolve any potentially harmful misunderstandings.
- Explanations should be detailed and repeated.

Implications for planners and policy makers

- Education initiatives such as DESMOND are likely to be more effective if delivered in an ongoing way.
- Sources of information should be user-friendly as appropriate to this age group.
- Nurse-led care should be encouraged with an emphasis on continuity and emotional support.

regarding coma and hypoglycaemia. Some respondents were significantly ill-informed about their risks which might result in poorly managed hypoglycaemic crises, with dangerous consequences. Conversely, many patients strongly feared hyperglycaemic coma for which they were at very low risk. This raises the question of whether the education they have received sufficiently highlighted the real dangers, while addressing unfounded fears which caused undue anxiety.

Patients appeared to value the initial education they received highly, particularly those who had attended courses. However, the information appears to attenuate over time. It has been shown that older people with diabetes have reduced learning compared with the general population.^{22,23} Although most patients acknowledged that they had forgotten a lot, most did not actively seek further advice. Large-scale evaluation of the DESMOND programme has shown it to be effective in altering certain lifestyle outcomes (e.g. weight loss) 12 months after attendance.²⁴ However, after three years of follow-up, the only significant benefit from the programme was in the 'illness beliefs score'.²⁵ This score was generated from questionnaires enquiring about the perceived understanding of disease and thus would not have identified those who had strongly held misunderstandings. Our findings reflect the conclusions drawn by those researching the effectiveness of DESMOND²¹ and the Department of Health²⁶ that an ongoing model of education would be optimal. The DESMOND programme is already trialling a new model which provides four additional sessions over two years.³ However, our findings suggest that people require consistent re-education throughout the duration of their disease, as this may be over 20 years in some patients. This is particularly relevant for those whose management has changed significantly over time, for example, by starting insulin therapy.

While some patients valued written information, it was often not read. It may not be legible for those with sight difficulties and can be out-dated. It was strongly expressed that face-to-face interaction was the most

important aspect of information giving. These patients' surprise and some misgivings regarding financial incentives for doctors to undertake basic processes of diabetic care are consistent with other studies.²⁷

This study indicates the need to improve diabetes service in some key areas. Emotional support should be explicitly offered to all patients, and they should be informed and involved in their management. We suggest that, as part of diabetes care, there is a need for consistent ongoing re-education of people with diabetes involving actively assessing areas of misunderstanding or doubt. This could potentially be achieved within the current structures of nurse-led clinics. Nurse-led care was appreciated by the patients and has been shown to be effective.^{28,29} Continuity of care was highly valued.

To conclude, this study has raised key issues in relation to quality of care and diabetes education for older people. The older people interviewed valued person-centred care and being kept informed about their condition. These people valued face-to-face education delivered in a continuous manner. A need for actively addressing misunderstandings amongst older people living with diabetes was identified. Further study is needed to investigate if these values and needs differ regionally or among different patient groups. This study has clear, achievable implications for change both at a local and policy level which could improve services for older people living with diabetes (see Box 1).

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CONFLICTS OF INTEREST

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Appendix

Interview schedule

1. Context – briefly tell me how long ago you were diagnosed with diabetes and what has happened since.
 - a. How well do you think your diabetes is controlled?
2. What do you think about the care you have received from the practice?
 - a. What is the best aspect?
 - b. What could be improved?
 - c. What matters most to you about the treatment that you get?
3. Do you feel you have the right amount of information about diabetes in order to help you manage your condition?
 - a. How was the information given, did you attend DESMOND, and what was your opinion of it?
 - b. What do you understand by what 'having diabetes' means?
 - c. Are you aware about what could happen if diabetes is not well controlled?
4. What do you think about the treatment you are receiving for your diabetes?
5. Were the risks and benefits explained? Is that important to you?
6. Do you always see the same doctor or nurse?
 - a. Is that important to you?
7. During consultations with doctors or nurses do you feel you are being listened to?
 - a. Do you feel your views are being taken into account?
 - b. What do you think you have contributed to decisions made about your diabetes?
 - c. Do you feel that your treatment plan is tailored to what matters to you?
8. Do you feel you get adequate emotional support for your diabetes?
Have you ever experienced an emergency related to your diabetes?
9. Do you know what could happen if your sugars went very low? Are you aware of what symptoms to look out for, and what to do?
10. Do you feel that you can get help when you need it?
 - a. For this research I'm specifically asking older people about their opinions. Do you feel you have been treated differently (in a good or bad way) due to being older?
 - b. Do you think there can be any improvements to specifically help people in your age group?
11. Can you think of one thing that would improve your quality of life?
12. Doctors are paid more by the government if they reach certain targets (for example, if a certain proportion of patients with diabetes have a low cholesterol, or blood sugars in the healthy range). What is your opinion about this?