

Education for people with type 2 diabetes: What do patients want?

Jackie Sturt, Hilary Hearnshaw, Julie H Barlow, Jenny Hainsworth, Sandra Whitlock

Introduction

In the UK, diabetes health policy has focused on encouraging people to become more knowledgeable about their condition and treatment regimen and on improving the self-management abilities of people with diabetes (Department of Health, 2001; 2002). Yet guidelines issued by the National Institute for Clinical Excellence (2003) for diabetes patient education provide little guidance in curriculum content and support processes which could assist NHS providers in the design of patient education programmes to help people self-manage their diabetes. This paper presents the findings of a study to identify, from the patient perspective, the self-management educational and support needs for people with type 2 diabetes.

Since the late 1990s, NHS policy has aimed to improve the self-management abilities of people living with chronic disease. Self-management education, in which people engage in active partnership and decision-making in relation to disease management, is recommended by *The Expert Patient* report (Department of Health [DoH], 2001) and the National Service Framework (NSF) for diabetes (DoH, 2002). People engaged in self-management programmes have been shown to have improved physical and physiological health (Barlow et al, 2000; Lewin et al, 1992; Lorig and Holman, 1993; Lorig et al, 1999). Primary care trusts (PCTs) are required to implement self-management programmes for key chronic disease groups, including diabetes, by 2007 (DoH, 2001) – yet there is little guidance on the form that such programmes should take or curriculum content.

The lack of policy guidance on curriculum design and content is echoed in the absence of literature to identify, from the patients' viewpoint, the educational and support requirement for effective self-management to take place. The literature does present a suggested curriculum, but this is prioritised by a set of health professional-determined

subject areas (e.g. Colagiuri et al, 1995). This led Peel and colleagues (2004) to note that research conducted on needs assessments has constrained the participant into a format pre-determined by health professionals, rather than shifting the focus to the patient and thereby identifying the patient's own views of his/her educational and support needs for successful self-management.

The Long-term Medical Conditions Alliance (LMCA) reported on the Living with Long-term Illness (LiLL) project, which stated that work on developing expert self-management programmes for patients should commence with asking them what they needed to better manage their health (Cooper, 2001). Hence, the aim of this research is to identify, from the patient's perspective, the diabetes self-management educational and support needs.

Methods

Research design

Focus groups were used for this qualitative study. Focus group research is an established research method, which allows data to be generated by interaction between participants and between the facilitator and participants (Barlow et al, 1999; Kitinger, 1994). It allows ideas to be stimulated, clarified

ARTICLE POINTS

1 It is important to identify diabetes educational needs from the patients' perspective.

2 Patients need to develop a level of knowledge if they are to effectively self-care.

3 Patients need to be able to relate diabetes knowledge to their personal situation.

4 They need to understand the process of behavioural applications.

5 They need health professionals to support specific behaviour change.

6 People with type 2 diabetes need to be offered structured education programmes.

KEY WORDS

- Type 2 diabetes
- Self-management
- Educational needs
- Support needs

Jackie Sturt is R&D Lecturer in Social Sciences, Warwick Diabetes Care, Centre for Primary Health Care Studies, University of Warwick, Coventry, Hilary Hearnshaw is Reader/Director of Research, Warwick Diabetes Care, University of Warwick, Julie H Barlow is Professor of Health Psychology, Interdisciplinary Research Centre for Health, Coventry University, Jenny Hainsworth is Clinical Psychologist, Interdisciplinary Research Centre for Health, Coventry University, and Sandra Whitlock is Research Fellow, Centre for Primary Health Care Studies, University of Warwick.

Table 1. Characteristics of the study population (n=23)

| | | |
|--|--------------------|----------|
| Recruitment | Local press | 18 (78%) |
| | Primary care | 5 (22%) |
| Socio-economic group III (non-manual) and above | | 17 (74%) |
| Gender | Male | 16 (70%) |
| | Female | 7 (30%) |
| Ethnicity | White | 22 (96%) |
| | Asian British | 1 (4%) |
| Age | Over 50 years | 16 (70%) |
| | 50 years and under | 7 (30%) |
| Presence of co-morbidity | | 12 (52%) |
| New diagnosis in last year | | 10 (43%) |
| Initiated oral therapy in last year | | 6 (26%) |
| Initiated insulin in last year | | 7 (30%) |

and expanded, and encourages participants to discuss a range of questions while ensuring, as far as possible, that the researchers fully understand the views expressed by the participants.

Six focus groups were convened and participants were allocated to a group according to whether they had recently been diagnosed with diabetes or changed therapy within the previous 12 months (i.e. two groups of recent diagnoses, two groups on new oral therapy and two groups with recent insulin initiation). Different stages of treatment were chosen to identify whether patient needs varied with the duration and experience of treatment. Warwick Diabetes Care (WDC) user group, a lay advisory group, advised on the study design. The local research ethics committees granted ethical approval, and Diabetes UK funded the research.

Participant recruitment and population

Recruitment to the focus groups was carried out by press releases in local newspapers and through leaflets placed in primary care centres in both urban and rural locations within the West Midlands. Forty-four people responded to the press release, of whom 41 subsequently confirmed their appointment. Five participants were

recruited from primary care centres. The eligibility criteria for inclusion in the study was a diagnosis of diabetes, or change of therapy to oral medication or insulin within the previous 12 months.

Twenty-three people took part in the six focus groups (see Table 1 for participant characteristics), each of which was led by a member of the research team. Each focus group discussed questions from a pre-determined schedule (Table 2) for between 75 and 90 minutes.

The first focus group was used as a pilot to test the schedule and this resulted in a more flexible approach to the introduction of topics during subsequent focus group discussions. Each focus group was audio-recorded with the participants' consent. The tapes were then transcribed verbatim and analysed using NVivo, a piece of qualitative software (www.qsrinternational.com). Three of the focus group transcripts were also re-analysed by three members of the WDC user group to identify any subtleties within the data which may have been more evident to those who could directly relate to the participants' experiences (Figure 1).

Results

Four key components to educational programmes designed to facilitate confident self-management of diabetes emerged from analysis of the data (Figure 2). These were:

- knowledge requirements
- personal data monitoring
- specific behavioural applications
- general behavioural applications.



Figure 1. Three members of the user group analysing focus group transcripts.

PAGE POINTS

1 Participants wanted to be able to understand how to relate their newly acquired knowledge to their own situation.

2 Six focus groups were convened and participants allocated to a group according to whether they had recently been diagnosed with diabetes or changed therapy in the previous 12 months.

3 Twenty-three people took part in the six focus groups. Each group discussed questions from a pre-determined schedule (Table 2).

Knowledge requirements

A certain level of knowledge is an essential prerequisite to ensure that people with diabetes initiate and maintain appropriate behavioural change to self-manage their diabetes confidently. Participants were clear that they needed to understand blood glucose, physiological interactions, diabetes complications and medication. For this they needed to know the facts concerning optimal blood glucose parameters, measurement and the impact upon blood glucose of, for example, food, exercise and stress. Participants who were taking medication wanted to know why they required it, the name, dosage and mode of action. Most participants wanted to know about the possible complications that might occur so that they could keep a look out for the symptoms.

'I've picked up the different leaflets. I keep reading them from time to time and suddenly it struck me that they keep going on about your feet and having them examined. Nobody anywhere has ever told me to have my feet examined and why you have them examined.'

Personal data monitoring

The participants also wanted to be able to understand how to relate this knowledge to their own situation: to be able to monitor and interpret their own data by identifying patterns and relating these to their diet and exercise regimen. Having an understanding of blood glucose and its measurement enabled participants to collect and interpret their own measurements and to understand the fluctuations caused by physiological interactions. This enabled them to understand that what they did and ate ultimately impacted upon their personal blood glucose levels.

'I have noticed [...] I've lost a couple of stone... as the weight goes up so the [blood glucose] readings go up, it is very closely linked.'

Knowledge of the possible complications and their symptoms meant

Table 2. Focus group schedule

1. Types of information, education and support required as a consequence of diagnosis/change in therapy.
2. At what points in time were different pieces of information, education and support required?
3. In what ways were/are self-management needs being met?
4. How have the participants contributed to meeting their own self-management needs?
5. How are health information and services used?
6. How do the participants manage their own diabetes and general health needs?
7. What types of services should be developed to meet their self-management needs?
8. Attitudes surrounding lay-led and professional-led support and services.
9. What do the participants think health professionals think they need?

that participants could be more aware of the first signs of the development of complications. They therefore wanted to be able to identify the processes involved in monitoring and/or preventing long-term complications. Knowledge of their personal medication dosage, and comparison of this with that taken by peers, enabled participants to monitor how well their diabetes was being managed in relation to others.

'I know some people only take a very small dose and some take a massive dose three or four times a day [...] and you don't know where you are in that category.'

Specific behavioural applications

For some participants an understanding of the process was the first step in taking control of their diabetes, to achieve balance in their blood glucose levels and to avoid or manage hypoglycaemic episodes.

'The only person really who can do you any good is yourself. At the end of the day, a doctor can give you the best medication in the world, the dietitian can tell you exactly what to eat to keep it, but she cannot make you eat it. And he can't make you take the prescription at the time he gives it and that he says you should take it.'

PAGE POINTS

1 Knowledge of the possible complications and their symptoms meant that participants could be more aware of the first signs of the development of complications.

2 Participants also wanted the support of health professionals in helping them to apply their acquired knowledge and personal data to their diabetes self-management.

3 Participants valued care that enabled them to self-manage with confidence and which, in turn, fostered a greater sense of self-control over their health care.

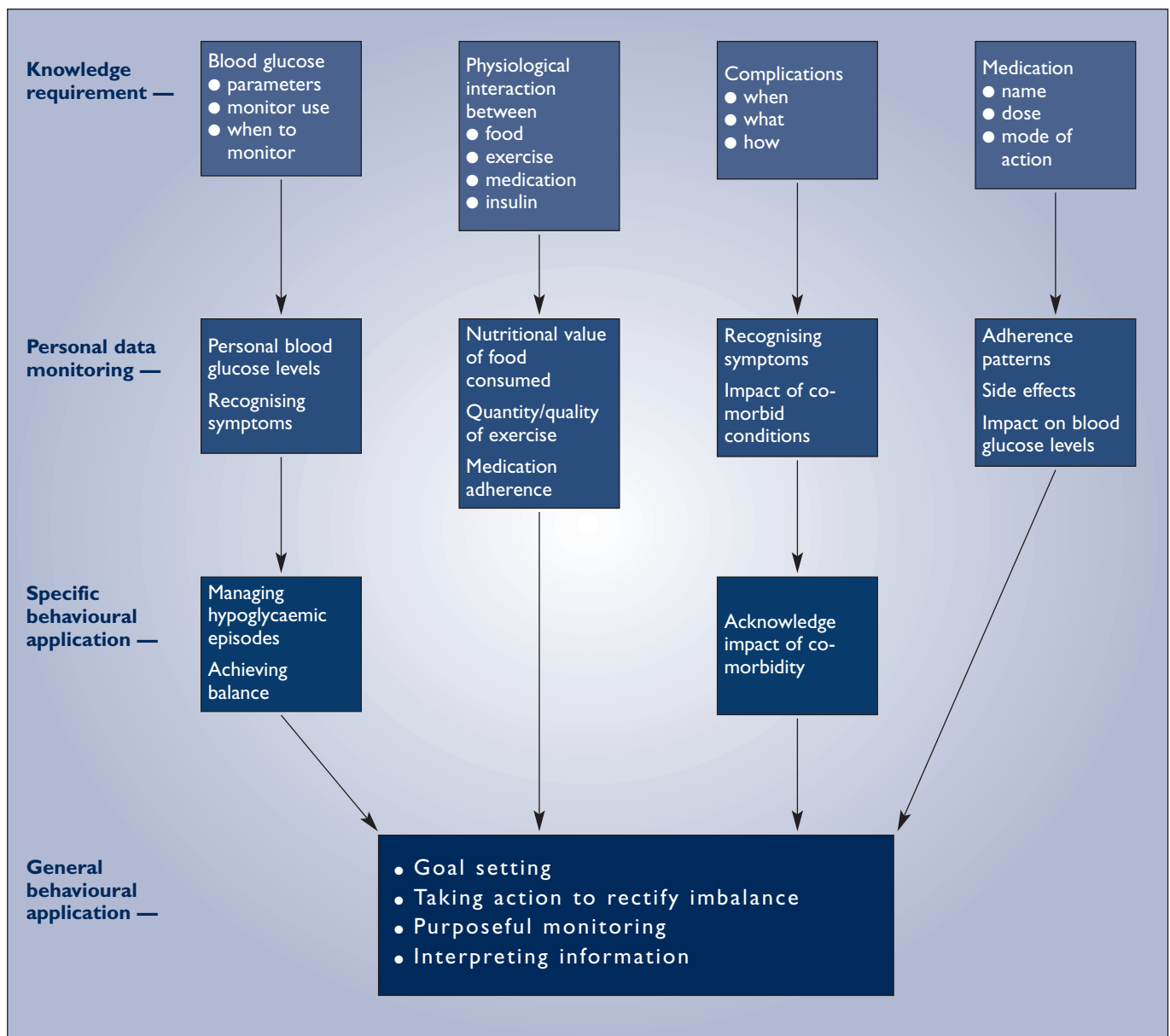


Figure 2. Self-management educational syllabus for type 2 diabetes.

General behavioural applications

Participants also wanted health professionals to support them by helping them to apply their acquired knowledge and personal data to their diabetes self-management. Identifying and setting goals for specific and general behavioural change was seen as necessary to help people initiate the behavioural changes that resulted from acquiring knowledge. Mechanisms for meeting these needs were identified, including some innovative suggestions such as cookery courses and exercise classes on prescription. Such ideas are apposite given the effectiveness of similar lifestyle interventions in the reduction of

incidence of type 2 diabetes (Knowler et al, 2002).

Participants valued care that enabled them to self-manage with confidence and which, in turn, fostered a greater sense of self-control over their health and care.

Discussion

Our findings suggest that our focus group members were able to articulate and justify their own educational requirements. Their views may provide useful guidance to practitioners seeking to create or improve a structured education programme for people with type 2 diabetes. It is noteworthy that participants at each change situation

PAGE POINT

1 The key educational needs are provision of information, training in personal monitoring, and specific and general goal setting and evaluation.

expressed similar educational needs, even though participants who had recently been initiated onto insulin would have received a greater input of education.

The key educational needs are the provision of information, training in personal monitoring and specific and general goal setting and evaluation. While the provision of information should not pose any great difficulty, the need for training to enable people with diabetes to monitor their own health and introduce behavioural changes in response may be more difficult. Participants wanted clinicians to support and advise them in goal setting and behavioural change, a demand that also has implications for the further training of diabetes nurses and for the duration and frequency of appointments.

There are a number of limitations to our research, which do need to be considered and which mean that results cannot be assumed to represent the views of all people with diabetes.

First, this study is not based on a representative sample of the UK population with diabetes. Our self-selected study population comprised mainly white, middle-aged, middle-class males. It may be that this group was inspired to participate because the focus groups were organised by university staff and this group felt comfortable with their association with us.

Second, there was a very poor response rate from our invitations to patients at GP practices. We do not know whether the focus group discussions would have been different if a greater number of this group had participated in the research.

Third, we were concerned about the very low representation from ethnic minority groups. Our initial recruitment had not produced any ethnic minority participants, so efforts were made to gain their participation through speaking to a community gathering of local Punjabi-speaking people with diabetes. Regrettably, although four people agreed to join a focus group, only one attended. It is possible that participation may have

been increased by offering a separate focus group facilitated by a Punjabi speaker.

Finally, we were concerned about the small number of participants in each focus group, due to non-attendance on the day. Despite this, homogeneity of the groups was maintained, the importance of which is discussed by, for example, Kitzinger (1994). Homogeneity was determined by the participants' relationship to a change situation (i.e. new diagnosis, or change to oral medication or insulin), and because all participants had in common their diabetes and the experience of a change in treatment regimen, thus enabling valuable discussions to ensue. In future research, however, it would be desirable to anticipate the effect of non-attendance, particularly where a minimum number of participants is needed.

Conclusion

This small study suggests that people with type 2 diabetes want a structured education programme that incorporates education, personal data monitoring and training in behaviour change. The results of this study may be of value to those involved in developing, delivering and evaluating education and self-management programmes for people with type 2 diabetes.

The findings from this study have informed the development of The Diabetes Manual Programme (Sturt et al, 2004), which has been designed to enable patients to gain confidence and skills quickly and progressively in the management of their diabetes. It incorporates information, goal setting and evaluation, accompanied by a relaxation tape and a tape of frequently asked questions. The relaxation tape is part of the stress reduction component of the programme. The manual itself deals with anxiety and depression in some detail. This is justified because anxiety is a barrier to change (in this case behavioural change) and depression is an established complication of diabetes. The manual presents both an

PAGE POINTS

1 The investigators' findings suggest that their focus group members were able to articulate and justify their own educational requirements.

2 The key educational needs are provision of information, training in personal monitoring, and specific and general goal setting and evaluation.

3 The results of this study may be of value to those involved in evaluating education and self-management programmes for people with type 2 diabetes.

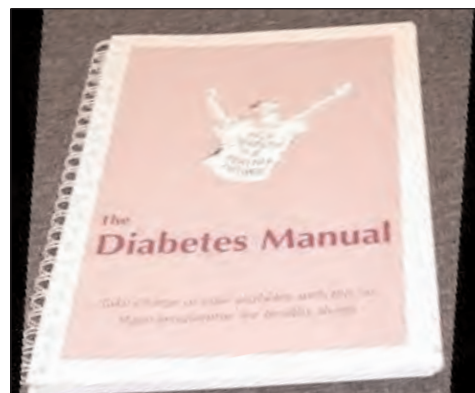


Figure 3. *The Diabetes Manual* front cover.

educational syllabus for learning about diabetes and a theory-based approach founded on adult learning and psychological theory of self-efficacy, to help people to adopt new behaviours that are therapeutically desirable. *The Diabetes Manual* (Figure 3) is currently undergoing a randomised controlled trial in primary care. ■

ACKNOWLEDGMENTS

We would like to express our gratitude to the study participants, to Warwick Diabetes Care user group for their advice and assistance with this research, and to Diabetes UK for funding this study.

Barlow JH, Shaw KL, Harrison K (1999) Consulting the 'experts': children's and parents' perceptions of psycho-educational interventions in the context of juvenile chronic arthritis. *Health Education Research* **14**(5): 597-610

Barlow JH, Turner AP, Wright CC (2000) A randomised controlled study of the Arthritis Self-Management Programme in the UK. *Health Education Research* **15**(6): 665-80

Colagiuri R, Colagiuri S, Naidu V (1995) Can patients set their own educational priorities? *Diabetes Research and Clinical Practice* **30**(2): 131-36

Cooper J (2001) *Partnerships for successful self-management: the launch of the living with long-term illness (Lill) project report*. Royal College of Physicians, London

Department of Health (2001) *The Expert Patient: a new approach to chronic disease management for the 21st century*. DoH, London. Available at <http://www.dh.gov.uk/assetRoot/04/01/85/78/04018578.pdf> (accessed 05.04.05)

Department of Health (2002) *The National Service Framework for Diabetes: Standards*. DoH, London. Available at <http://www.dh.gov.uk/assetRoot/04/08/87/55/04088755.pdf> (accessed 05.04.05)

Knowler WC, Barrett-Connor E, Fowler SE, Hamman RF, Lachin JM, Walker EA, Nathan DM; Diabetes Prevention Programme Research Group (2002) Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. *New England Journal of Medicine* **346**(6): 393-403

Kitzinger J (1994) The methodology of Focus Groups: the importance of the interaction between research participants. *Sociology of Health and Illness* **16**(1): 103-21

Lewin B, Robertson IH, Cay EL, Irving JB, Campbell M (1992) Effects of self-help post-myocardial-infarction rehabilitation on psychological adjustment and use of health services. *Lancet* **339**(8800): 1036-40

Lorig K, Holman H (1993) Arthritis self-management studies: a twelve-year review. *Health Education Quarterly* **20**(1): 17-28

Lorig KR, Sobel DS, Stewart AL, Brown BW Jr, Bandura A, Ritter P, et al (1999) Evidence suggesting that a chronic disease self-management program can improve health status while reducing hospitalization: a randomised trial. *Medical Care* **37**(1): 5-14

National Institute for Clinical Excellence (NICE; 2003) *Guidance on the Use of Patient-Education Models for Diabetes*. Technology Appraisal No 60. NICE, London

Peel E, Parry O, Douglas M, Lawton J (2004) Diagnosis of type 2 diabetes: a qualitative analysis of patients' emotional reactions and views about information provision. *Patient Education and Counseling* **53**(3): 269-75

Sturt J, Hearnshaw H, Patel V, Ormerod R (2004) *The Diabetes Manual: Enhancing self-efficacy through structured patient education*. *International Journal of Behavioral Medicine* Vol 11, Sept 2004 (abstract)