

What do people want when it comes to diabetes education?

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Article points

1. Before embarking on a new, ambitious programme of structured education for the people with diabetes being seen by the author's team, it seemed sensible to firstly investigate the views and desires of the target population.
2. A questionnaire was used to obtain the opinions of people with diabetes on issues such as how they would prefer to receive more information about diabetes, preferred venues and times, and preferences for different topics.
3. The results of the questionnaire show that the educational preferences of respondents were for it to be delivered on a one-to-one basis in their local health centres on a weekday morning.

Key words

- Patient education
- Group sessions
- Questionnaire

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In 2003, the National Institute for Health and Clinical Excellence (formerly the National Institute for Clinical Excellence; NICE) found that although most people with diabetes were offered some education, the programmes often varied in length, content and delivery, and many were not evaluated. Additionally, of those professionals who delivered the education, few were trained to do so. It also appears that patients have very little input with regard to content, delivery or venues of educational programmes (Muhlhauser and Berger, 2000). However, patient education is now high on the Government's agenda and implementing structured education for people with diabetes has become a national priority.

There is no doubt that people with diabetes require some form of education. However, merely giving people advice and teaching them about diabetes does not guarantee that learning has taken place. Similarly, do healthcare professionals take into account the views and desires of people with diabetes?

Through videotaped encounters between people with diabetes and doctors or nurses, Holmstrom and Rosenqvist (2005) found that, despite intensive education and support, misunderstandings about both the condition and its treatment persisted in people with diabetes. Johnson et al (2005) also reported on the fact that most educational interventions have tended towards a professional-oriented perspective which ignores the expectations and capabilities of people with diabetes and ignores the communication skills and knowledge base of professionals.

On the other hand, improved outcomes have been achieved through education. Rachmani et al (2005) carried out a randomised controlled study of 165 people with type 2 diabetes, hypertension

and dyslipidaemia to elicit whether a patient participation programme showed any benefits over standard consultations. The researchers found that people in the participation programme showed a better clinical outcome, reflected in significantly lower values of major risk parameters, compared with those in the standard consultation group. Rachmani et al felt that this was due to intensified therapy prompted by the initiatives of people with diabetes and by better compliance.

According to Norris et al (2001), the effects of traditional educational interventions, the goal of which has been to improve glycaemic control and reduce the risk of long-term complications, have not been encouraging. On the other hand, some self-management programmes have had a beneficial impact on psychological well-being and quality of life (Norris et al, 2001; Steed et al, 2003), which are arguably more important than, or at least as important as, improvement in metabolic control.

Hunt et al (1998) reported on the difference between the goals of healthcare professionals

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1. The literature might seem confusing: on the one hand, researchers appear to be saying that patient education can still leave people with feelings of confusion and misunderstandings, but others report improved clinical outcomes as a result of education.
2. For healthcare professionals, group sessions are the most cost-effective way of delivering education.
3. On the other hand, in the author's experience few people with diabetes relish the thought of attending such sessions.
4. Before embarking on a new, ambitious programme of structured education for the people with diabetes being seen by the author's team, it seemed sensible to firstly investigate the views and desires of the target population.

and those of people with diabetes. Healthcare professionals' goals were rooted in optimum clinical outcomes, and failure to achieve these was viewed as people with diabetes being uncooperative. In contrast, the goals of people with diabetes stemmed from living with a chronic condition in the real world, where options and social power may be limited.

Hornsten et al (2005) interviewed 44 people with type 2 diabetes and found that they wanted to be valued as a person and not seen merely as a 'case' or a 'patient with a disease'. This type of depersonalised care has been highlighted by a number of researchers (Thomas et al, 1995; Winefield et al, 1996; Kralik et al, 1997). It seems sensible to suggest that if people with diabetes feel dissatisfied and devalued as a person, they are less likely to gain anything positive from their clinical or educational encounters with the professionals.

Muhlhauser and Berger (2000) argue that diabetes education programmes are crucial to both train and motivate people with diabetes to increase their quality of care and independence. However, the researchers point out that patient education has rarely been based on informed choice by the patient. Instead, it is more often used to get people with diabetes to comply with treatments that are assumed to be in their best interest. Muhlhauser and Berger emphasise the importance of informed patient choice to strengthen their autonomy and their 'right to to participate, or even to take responsibility for these medical decisions.' They also highlight the fact that involving patients in the decision-making process is particularly relevant for people with type 2 diabetes, as even perfect, long-term therapeutic co-operation will not eliminate complications of diabetes, but only reduce the risk of developing them in the future.

The literature, therefore, might seem confusing. On the one hand, researchers appear to be saying that patient education can still leave people with feelings of confusion and misunderstandings, but others report improved clinical outcomes as a result of education. The National Institute for Health and Clinical Excellence (formerly the National Institute for Clinical Excellence; NICE; 2003) defines structured patient education as:

'a planned and graded programme that is comprehensive in scope, flexible in content, responsive to an

individual's clinical and psychological needs, and adaptable to his or her educational and cultural background.'

However, some of the existing literature (e.g. Mulhauser and Berger, 2000) criticises patient education models as being too clinically orientated with little regard for the patients' wants or desires. Education appears to be physiologically driven, while at the same time being psychologically and sociologically bereft (Glasgow, 1999). Such approaches seem inadequate for people who strive for normality in a world which, for them, is most definitely not normal and never will be.

NICE (2003) has highlighted the effectiveness of group education sessions, but from whose point of view? For healthcare professionals, group sessions are the most cost-effective way of delivering education. In the present financial climate, and with the increase in the numbers of people with newly diagnosed diabetes, it could be argued that group education is the only way forward if healthcare professionals are to be able to provide education for the majority of people with diabetes.

On the other hand, in the author's experience few people with diabetes relish the thought of attending such sessions. Moreover, any education needs to incorporate the issues which are important to each person attending. The sessions should not be merely based on improving physical parameters, as it is often psychosocial issues which are having an impact on an individual's diabetes control.

Before embarking on a new, ambitious programme of structured education for the people with diabetes being seen by the author's team, it seemed sensible to firstly investigate the views and desires of the target population. Although it was never envisaged that all preferences could be accommodated, it was felt that some effort should be made to involve people with diabetes from the start. It was therefore decided to carry out a survey of the individuals attending the diabetes clinic at the author's hospital. The aim was to discover some of the preferences of attendees, with regard to not only learning more about diabetes, but also where, when and how they would like to receive the information.

Methods

All people attending the Wednesday diabetes clinic at the district general hospital in Stockport were asked if they would complete a short questionnaire (see *Appendix 1*). This clinic was chosen because it covers the greatest number and variety of people. In addition, it is the only clinic where both newly diagnosed and follow-up people attend.

The questionnaire was designed to be as simple as possible so that people could complete it while in the waiting area of the clinic. The questionnaires were distributed to all attendees by the clinic clerk. Questions included issues such as how people would prefer to receive more information about diabetes, preferred venues and times, and preferences for different topics. Completed questionnaires were placed in a sealed box within the clinic area.

Data from all of the questionnaires returned have been included in the final analysis, although some respondents failed to answer some of the questions. This was assumed to be because the people not completing the form either were called in for their appointment or chose not to answer certain questions. In all, 245 questionnaires were returned and analysed over a 4-month period.

Results

Breakdowns of the responses to questions 1 to 4 are provided in *Figures 1 to 4*, respectively. The total responses for each question add up to over 245 as many of the people responded by ticking more than one box. All of the responses were included in the final analysis.

Discussion

It is clear from the results of the questionnaire that the educational preferences of people were for it to be delivered on a one-to-one basis in their local health centres on a weekday morning, although this may reflect the age group as the majority of respondents (69.1%) were over 50 years old. The topics

that the respondents overwhelmingly required more information on were diet, long-term complications ('LT complications' on the questionnaire) and living with the condition.

Unfortunately, the capacity for every person with diabetes to be offered education on an individual basis is limited. This said, the majority of the people attending the clinic with type 1 diabetes are, in fact, educated in this way. This is mainly due to the limited space that has been available in the past for group education sessions. Increasingly, however, this is becoming less of an option because of the increasing numbers of people being referred to the service. Education on a one-to-one basis is, therefore, being scaled down in favour of group sessions, owing to a lack of time and available staff.

The survey also highlights the greater expectations of people with diabetes today, particularly with regard to remaining within their own locality, and this mirrors the Government's concept of delivering health care on people's doorsteps (Department of Health [DoH], 2006).

Although it may not be possible to accommodate the preference for one-to-one teaching, there is probably a much greater capacity to endorse the desire for local learning. Providing education for groups of people with diabetes within their own area, in surroundings which they would find familiar, at a time which they prefer, and on subjects which they are keen to learn more about goes part way to conforming to their requests. This provides a starting point on which to base any future education sessions.

A major goal of healthcare professionals caring for people with diabetes is to ensure that metabolic control is optimum and that the risk of long-term complications is reduced to a minimum, and, to that end, individuals can sometimes be furnished with a surfeit of knowledge about diabetes which is at best overwhelming and at worst off-putting.

In this survey, people with diabetes have indicated a general dislike for group education, yet in order to make numbers

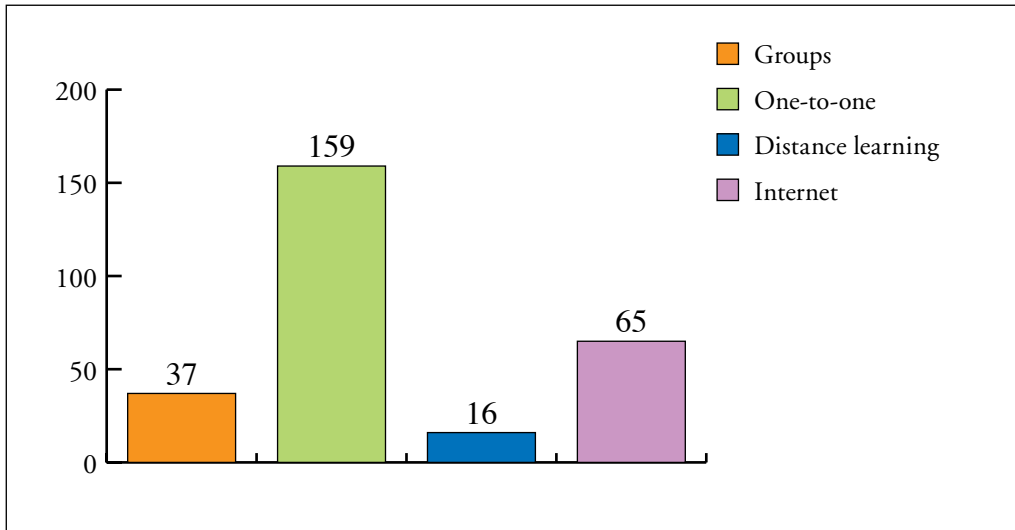


Figure 1. Number of responses, by option, to question 1: 'How would you like to receive more information about diabetes?'. Responses specified in the 'Other' option were: 'by post', 1; 'GP', 1; 'GP with special interest', 1; 'leaflets', 1; and 'walk-in clinic', 1.

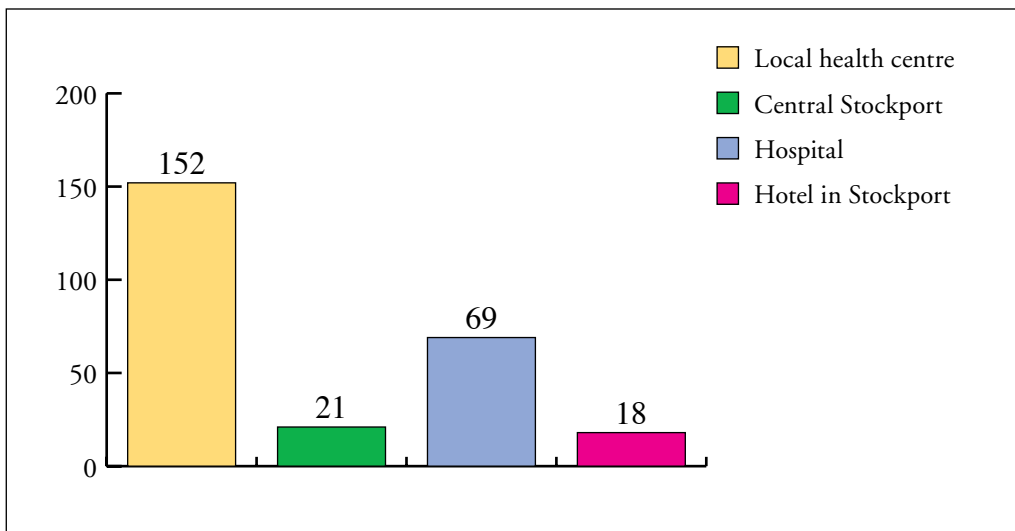


Figure 2. Number of responses, by option, to question 2: 'Where would you like to receive this information?'. Responses specified in the 'Other' option were: 'home', 3; and 'on line', 2.

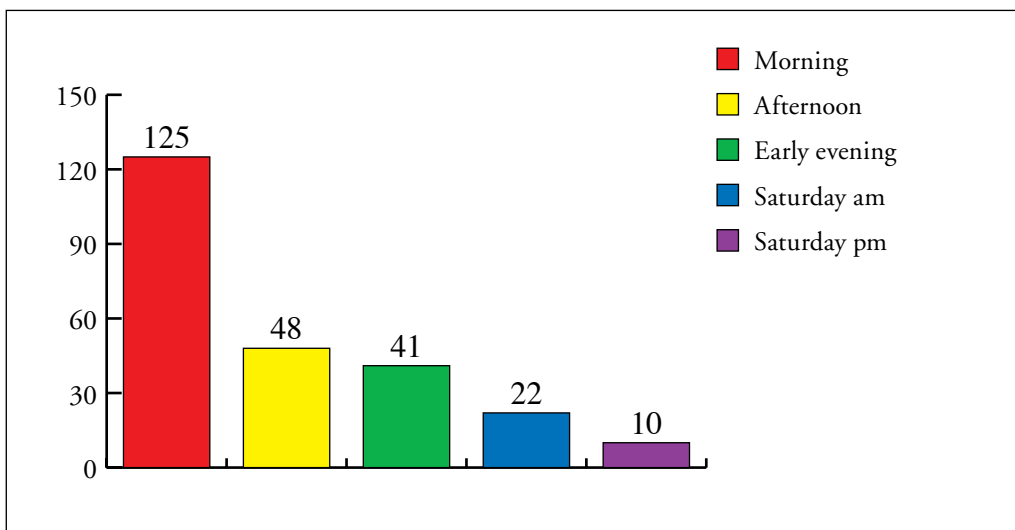


Figure 3. Number of responses, by option, to question 3: 'What time of day would you prefer?'. Responses specified in the 'Other' option were: 'anytime', 1; and 'not specified', 1.

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1. There were limitations to the questionnaire used in the survey in that it was not validated before use and no pilot study was carried out before the commencement of the study.
2. However, the results do provide a starting point for the delivery of patient education programmes.

Figure 4. Number of responses, by option, to question 4: 'Which areas of diabetes would you like more information on?'. Responses specified in the 'Other' option were: 'cures', 1; 'depression', 1; 'drugs', 1; 'everything', 1.

more manageable, this has to be the way forward, the author feels. People with diabetes can gain a great deal from attending group sessions, and, although apprehensive at the start, many have expressed their enjoyment when such sessions have ended. In order to motivate people to accept group learning, a must-have aspect of any session is that it is fun to attend. People are much more likely to attend again if their first experience was an enjoyable one.

Hughes et al (1999) reported on the success of group sessions for obese people with poorly controlled diabetes who had not lost weight during standard intervention (one-to-one dietary advice sessions). They used a mixture of interactive discussions, activities and lectures designed to encourage the development of skills. The researchers found that individuals who attended the group sessions, relative to those who only attended for individual tuition, were 1.9 times more likely to lose weight, indicating that peer support may be a factor in following recommendations.

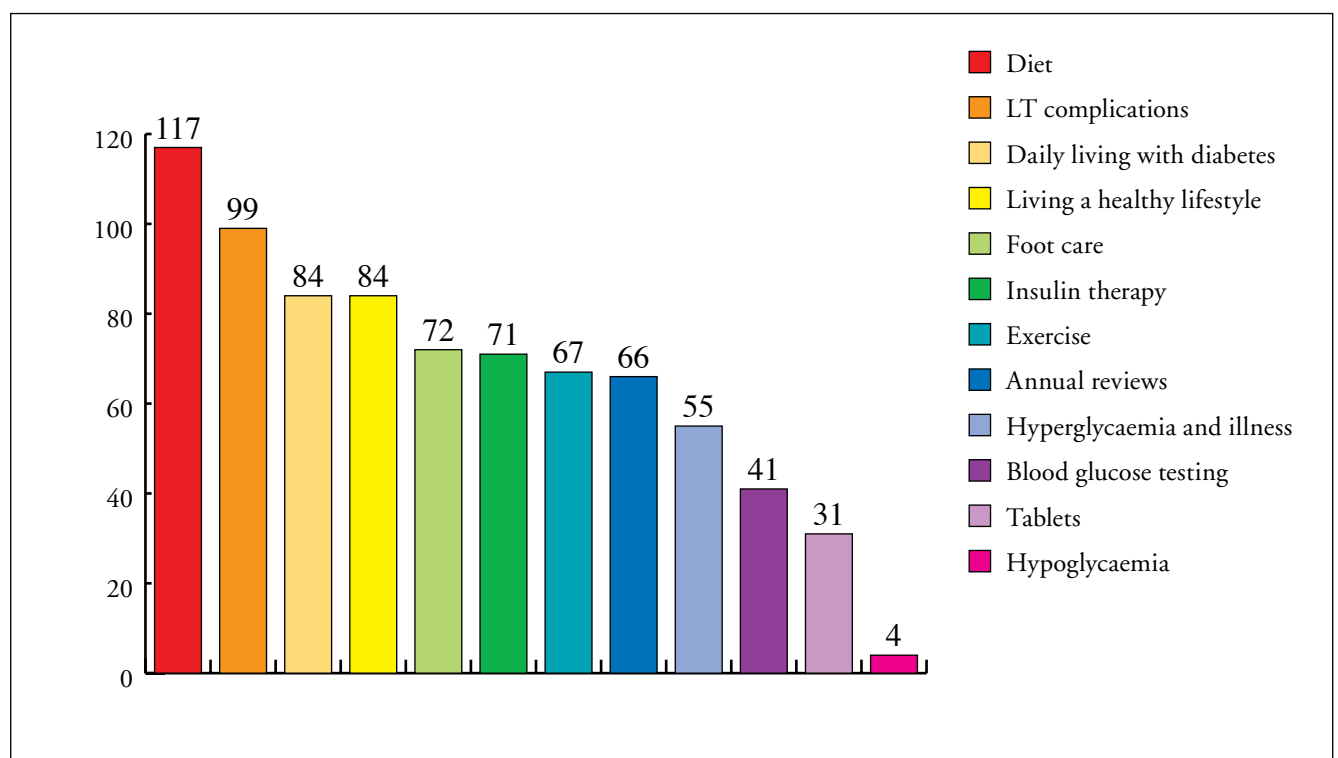
Likewise, Everett and Kerr (1998) found positive clinical results following group education sessions for people with newly

diagnosed type 2 diabetes. In addition, the satisfaction of these individuals was high following the sessions. However, attendees found parking difficult in the hospital environment (Knott et al, 2005), giving credence to the need for education to be locally based. Although perhaps not people's first choice, it appears that group education may be more effective and more enjoyable than is initially perceived.

Study limitations

There were limitations to the questionnaire used in the survey in that it was not validated before use and no pilot study was carried out before the commencement of the study. In addition, some of the terminology may have been misleading or unfamiliar to some respondents (such as 'LT complications' and 'hyperglycaemia') and this may account for some of the missing data. A further bias may have been introduced by this survey only being undertaken in people attending a hospital-based diabetes clinic. Carrying out the same survey in a primary care setting would provide a useful comparison.

However, the results do provide a starting point for the delivery of patient education programmes.



Conclusions

The people in this survey were very clear as to their wants and desires with regard to diabetes education. The literature review, coupled with the results of the survey, has provided a framework on which to build a patient-centred, informative and enjoyable programme of education, although, in reality, the true value of such a programme cannot be ascertained until it is conducted and evaluated using clinical, educational and satisfaction outcomes.

While all elements of the educational needs of people with diabetes cannot be met because of limited resources, it is possible to ensure that what is provided incorporates the essence of people's wishes.

The Government has stipulated the requirement for primary care trusts, this year, to provide structured patient education which is evidence-based, quality assured, audited and provided by trained educators (DoH, 2005). In order to meet these targets, healthcare professionals find themselves in a position of compromise. With the explosion in numbers of people with newly diagnosed diabetes, the increasing numbers of people transferring to insulin (Mulnier et al, 2005) and the dire financial state of the health service, it is not always possible to carry out individual education or provide exactly what people with diabetes would like. However, some is better than none, so the author and her team intend to accede to at least some of the wishes of the people they care for with diabetes.

In Stockport, the primary care trust has recently trained two educators to implement the X-PERT Programme for people with type 2 diabetes. In addition, plans are also underway to improve and extend the existing group education sessions, in order to deliver them locally, to cover subjects requested by the participants and to include psychological, as well as clinical, outcomes in their evaluation. It is intended that learning needs assessments will be carried out with all candidates prior to enrolment into the education sessions. Quality assurance will be met by using the criteria for both curriculum and evaluation specified by the Patient Education Working Group (DoH, 2005): the purpose and focus of the programme, the information collected for evaluation, the need

for judging the effectiveness of the programme and the dissemination of the results.

This mammoth task will not be resolved overnight; however, it is now possible to move forward in the knowledge that at least some of the requests of people with diabetes are being met. ■

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What do people want when it comes to diabetes education?

‘While all elements of the educational needs of people with diabetes cannot be met because of limited resources, it is possible to ensure that what is provided incorporates the essence of people’s wishes.’

Preferences for learning about diabetes

This questionnaire is designed to find out how, where and when you would like more information regarding your diabetes. We would also like to know which areas of diabetes you would like information on.

Please tick the boxes which represent your preferences.

1. How would you like to receive more information about diabetes?

a) Groups

b) One-to-one

c) Distance learning

d) Internet

e) Other (please specify)

2. Where would you like to receive this information?

a) Local health centre

b) Central Stockport

c) Hospital

d) Hotel in Stockport

e) Other (please specify)

3. What time of day do you prefer?

a) Morning

b) Afternoon

c) Early evening

d) Saturday am Saturday pm

4. Which areas of diabetes would you like more information on?

a) Diet

b) Exercise

c) Foot care

d) LT complications

e) Annual reviews

f) Hypoglycaemia

g) Hyperglycaemia and illness

h) Blood glucose testing

i) Insulin therapy

j) Tablets

k) Daily living with diabetes

l) Living a healthy lifestyle

m) Other (please specify)

5. Which age group are you in?

a) 16–30

b) 31–50

c) 51–65

d) 66+

Appendix 1. The questionnaire used in the survey of people’s educational preferences.