

People's educational needs following a diagnosis of diabetes

Karen Turner

Article points

1. The aim of this qualitative study was to use semi-structured telephone interviews and patient-held diaries to explore patients' perspectives on the diabetes education they were receiving.
2. This study also looked at the impact of diabetes on individuals with diabetes, including changes they would like to see.
3. In order to explore people's views and experiences when first diagnosed, only people who were within the first 2 years following diagnosis were included.

Key words

- Education
- Telephone interviews
- Patient-held diaries

Diabetes education, that is effective and appropriate to individuals' needs, can enable them to make positive lifestyle changes – resulting in improved life expectancy and quality of life. This may also reduce the financial burden to the NHS. The aim of this qualitative study was to explore people with diabetes' perspectives on the education they were receiving using semi-structured telephone interviews and patient-held diaries. The study also aimed to gain an insight into what people need to manage their diabetes effectively, in order to encourage a partnership approach between people with diabetes and healthcare professionals. This study also looked at the impact of diabetes on individuals with the condition.

It is well known that poorly-controlled diabetes can lead to blindness, coronary vascular disease, renal failure and amputation of limbs. Watkins et al (2003) reported that diabetic nephropathy is one of the most common causes of renal failure, and the Department of Health reported that diabetic retinopathy is the leading cause of blindness in the UK among people of working age (DoH, 2000). With this in mind, structured care and education could be a way to 'increase the quality of life for people with diabetes by minimising the risk of long-term complications, thereby reducing the morbidity and healthcare costs associated with both type 1 and type 2 diabetes' (Diabetes UK, 2004).

Methodology

The aims and objectives of this study were to explore people with diabetes' experiences and views on the education they receive. A qualitative approach based on Grounded

Theory (Glaser and Strauss, 1967) was used in order to tease out themes from the data, rather than testing a predetermined hypothesis.

The timescale available for this study was restricted; therefore, the sample size was limited by the total population size; 34 individuals met the study criteria and 23 agreed to participate.

Sample population

In order to explore people's views and experiences when first diagnosed, only people who had been diagnosed in the last 2 years were included. This allowed analysis of individual views at a stage when people are still developing their knowledge and understanding of diabetes.

The sample was split into two groups: group 1 included seven people with type 1 or type 2 diabetes of less than 6-months duration; group 2 (n=16) had type 1 or type 2 diabetes of 1–2 years' duration. Group 1

Karen Turner is a DSN,
Colchester General Hospital.

kept diaries for 6 weeks and group 2 and took part in a semi-structured telephone interview.

While individuals were recruited from diabetes clinics and educational sessions run by DSNs, all those taking part in the study were managed by both primary and secondary care teams. The study therefore excluded people who were only being seen in primary care; although, at the time of this study, all structured education in groups was delivered in primary care.

Approval for the study was obtained from the local research and ethics committee, Essex Rivers Healthcare Trust and Local Research and Development. The hospital diabetes team was made aware of the study and permission was granted by the consultant physicians prior to inviting their patients to take part in the study.

Results

A number of themes emerged from the data. These included specific education requirements, additional requirements that people felt would enable them to adjust to the diagnosis of diabetes, and the emotional and social impact of living with diabetes. The data also offered insights into individuals' perceptions of the quality of diabetes care they have received. For those in group 1, three key themes were identified from the data. These were as follows.

- Education.
- Adjustment to diabetes.
- Support on diagnosis.

For people in group 2, the key themes identified were as follows.

- Education.
- Health impact and lifestyle changes.
- Patient autonomy.
- Quality of support.

Education

For people in group 1, there were no major complaints of education being misunderstood, but there were concerns around the lack of opportunity to

have questions answered by healthcare professionals. One individual reported:

'Since I became ill at the end of October last year, I have had no support or information to help me come to terms with or manage my diabetes.'

This resulted in feelings of negativity about their diagnosis. Some individuals in group 1 felt that a lack of educational support following diagnosis impacted on their diabetes management later on. One respondent said:

'I was so put off with all the conflicting advice ... that I haven't called ... since.'

On some occasions, this prevented them from seeking further advice.

For those in group 2, eight people found access to education and ongoing support lacking. It was suggested that education should be revisited a number of years following diagnosis. In this group, 11 people indicated that they were provided with basic information on diabetes, but found this largely inadequate. One respondent said he/she had to 'educate myself'.

People searched for education and support from various sources, such as: the Internet, helpline numbers from the hospital, helplines at work and Diabetes UK. Written information, although useful, was found to duplicate advice and repeat information they already knew. By contrast, some respondents said they received too much information when first diagnosed.

One of the recurrent issues identified within many of the themes for people in group 1 and group 2 was dietetic support. This ranged from only being given basic dietary advice, delays in seeing a dietitian or no advice. One respondent said:

'I've been waiting since February [6 months] to hear about an appointment with a dietitian.'

Page points

1. A number of themes emerged from the respondents' data. These included specific education requirements, additional requirements that respondents felt would enable them to adjust to the diagnosis of diabetes, and the emotional and social impact of living with diabetes.
2. For people in group 1, there were no major complaints of education being misunderstood, but there were concerns around the lack of opportunity to have questions answered by healthcare professionals.
3. For those in group 2, eight people found access to education and ongoing support lacking..
4. People searched for education and support from various sources, such as: the Internet, helpline numbers from the hospital, helplines at work and Diabetes UK

Page points

1. Six group 2 respondents perceived that dietary education provision needed improvement.
2. Group 2 respondents' perceived needs on the level of education varied widely: five individuals found that the education provided was too complicated or too much, with one commenting that answers were too technical.
3. Some wanted to go 'back to basics' and some preferred a basic course for people who had not heard of diabetes, for example; a more staged delivery with a diabetes specialist; somebody to contact immediately; and continuation of advice with one person, such as a diabetes nurse.
4. Of the six group 2 respondents who reported receiving structured education, three said it was inadequate.
5. In the early stages of diagnosis, respondents in both groups mentioned feelings of denial, shock, annoyance and isolation.

It was also commented that the dietetic information received needed to be ongoing and more structured. Six group 2 respondents perceived that dietary education provision needed improvement. Suggestions on how dietary education can be improved included: a diet sheet; cookery programmes and magazines to adapt their advice to include people with diabetes; courses in schools; and advice about eating when driving long distances.

Exercise advice was offered to some group 2 respondents but this was perceived to be basic.

Group 2 respondents' perceived needs on the level of education varied widely: five individuals found that the education provided was too complicated or too much, with one commenting that answers were too technical.

Some wanted to go 'back to basics' and some preferred a basic course for people who had not heard of diabetes, for example; a more staged delivery with a diabetes specialist; somebody to contact immediately; and continuation of advice with one person, such as a diabetes nurse. There was also a requirement for psychological support.

In contrast, six individuals found the education received to be too basic or lacking in frequency. They suggested that education should be ongoing and in-depth, and provide more information when diagnosed and when treatment is altered. Seven of the group 2 respondents suggested a mixture of basic and more complicated information tailored to the individual would be more appropriate – for example, a basic and intermediate course. One individual required the education in 'bite-size pieces' as, on diagnosis, people may be in shock. Requirements for education should include how to adjust insulin once the diagnosis of diabetes had been absorbed, and family members should also be educated.

Of the six group 2 respondents who reported receiving structured education, three said it was inadequate. The main complaints were that it was aimed at too

low a level and that it was patronising, with inadequate time to interact with other people with diabetes. Most of the reports of poor education in the study came from the respondents who had not received structured education.

Adjustment to diabetes – health impact and lifestyle changes

Group 1

In the early stages of diagnosis, respondents in both groups mentioned feelings of denial, shock, annoyance and isolation; with difficulties in absorbing the information and the effects diagnosis had on their families. In some instances, those in group 1 found adjustment to diabetes difficult. Also, two people in group 1 perceived the information provided or offered at diagnosis as overwhelming. Group 1 respondents had already made some changes to their diet and exercise and some noticed changes in their mood. This was largely perceived as a result of fluctuations in their blood glucose levels.

Other group 1 respondents perceived feelings of relief and gratitude at having a diagnosis of diabetes as it explained why they felt unwell. They were reassured when control had improved.

Group 2

Group 2 respondents voiced concern about the effects that diabetes had on their lives: from implications such as eating out and feeling different about themselves. There were few direct clues on requirements for education in this area, other than needing to address the concerns of the individual respondents. Only one respondent in group 2 said they were confident about his/her health in the future. For those in group 2 with type 2 diabetes, 63% voiced concerns over the future effects of their condition on their health, while only 40% of people in group 2 with type 1 diabetes voiced similar concerns.

For 80% of group 2 respondents with type 1 diabetes, the most worrying aspect was fear of hypoglycaemic events, especially

at night, and struggling to get the balance of insulin and exercise correct.

For group 2, 81% of respondents perceived that most lifestyle changes related to diet. This included changes to their eating habits; planning their day; and the impact of diet on their glycaemic control.

Patient autonomy

There was no display of autonomy by respondents in group 1. Some exhibitions of autonomy in diabetes management were noted from those in group 2 with type 2 diabetes. They largely put this down to being self-motivated, exercising common sense or being inquisitive. They felt this offered them a sense of control. This was demonstrated by asking to do their blood glucose testing and comments such as:

'I read everything I could.'

As experience grew, so did autonomy, with one respondent saying:

'Now I have more experience of diabetes, I have more autonomy or say in what I do.'

Another individual said:

'I've read a couple of books specifically on insulin-treated diabetes and get regular information from Diabetes UK and the American Diabetes Association, and I find these sources more clear, sympathetic and consistent than I got from the specialists.'

Some respondents felt they were autonomous about their diabetes management out of a sense of having to be, and others chose not to take advice from healthcare professionals as they felt they knew better.

Over 68% of individuals in group 2 found they were directed or told what to do to manage their diabetes. Of these, only one stated he/she was happy with this and four indicated they were unhappy. In contrast,

50% of people in group 2 felt choices about their diabetes management were negotiated with a partnership approach at both the nurse and consultant level. They were offered different treatment approaches and they decided which to try.

Support at diagnosis and quality of support

A key educational issue for individuals in group 1 was support at diagnosis. In this group, over half perceived delays in receiving support and education when they were initially diagnosed. Delays of 1, 3 and 4 months were reported in relation to dietetic input.

Dietetic support was an issue for 7 people in group 2. As with group 1, issues ranged from delays in referral of over a year to perceived poor advice. Respondents reported delays in follow-up appointments and initial referrals.

Consultations did not always meet people's educational requirements in group 2, and, in some cases, healthcare professionals were unable to answer their questions. In addition, three individuals felt that after initial consultation and advice, they were not offered ongoing support.

As with group 1, some of those in group 2 felt a lack of educational support on diagnosis had an impact on their diabetes control later on. Both group 1 and group 2 respondents experienced conflicting advice and indecision on their care from healthcare professionals.

Recommendations for practice

Both study groups found the standard of education they received ranged from good to poor, and 39% of all respondents experienced inconsistencies in the education they received. Inconsistencies included conflicting advice, omissions of information and differing levels of continued support. The inconsistencies of the education provided resulted in some respondents feeling negative about their diagnosis. Healthcare professionals' knowledge was questioned and respondents found that

Page points

1. There was no display of autonomy by respondents in group 1. Some exhibitions of autonomy in diabetes management were noted from those in group 2 with type 2 diabetes.
2. Some respondents felt they were autonomous about their diabetes management out of a sense of having to be, and others chose not to take advice from healthcare professionals as they felt they knew better.
3. Consultations did not always meet people's educational requirements in group 2, and, in some cases, healthcare professionals were unable to answer their questions. In addition, three individuals felt that after initial consultation and advice, they were not offered ongoing support.

Page points

1. The key message to take from these data is that 'one size does not fit all'.
2. The timing of education is, therefore, as important as the information being offered. At the initial point of diagnosis, the gap between appointments either needs to be shorter, or we need to offer open appointments so that people with diabetes can access support as and when they require it.
3. There are several recognised structured education courses for people with type 1 and type 2 diabetes.
4. The author's local diabetes network education sub-group is currently exploring ways of delivering structured education for people with type 2 diabetes in a more affordable way.

the advice given did not always meet their requirements, resulting in feelings of frustration and lack of confidence in the healthcare professional.

This study also confirmed that people with diabetes required different approaches. This varied from a structured group education programme to a one-to-one approach.

Many issues have been highlighted during the course of this study, and the main recommendations for changes in education are highlighted as follows.

- Improvements in accessibility and frequency of dietetic support are required, possibly by appointing a dedicated diabetes dietitian as part of the diabetes team to attend DSN-led clinics.
- Improvements in accessibility of structured exercise programmes, building on existing links with local sports facilities, such as the Life-Enhancing Activity Programme (LEAP) in Colchester.
- Patient education requirements need to be more accurately met before positive changes can be made in diabetes management. People with diabetes should be encouraged to take part in service planning within the diabetes team (lay members of diabetes networks and sub-groups). Representation needs to include people with both type 1 and type 2 diabetes.
- More appropriate access to healthcare professionals with the introduction of 'open' appointment systems and 'drop-in' clinic sessions in order that education and support is timely and appropriate.

Discussion

The key message to take from these data is that 'one size does not fit all'. It is important when planning future educational programmes that individuals' requirements are considered and provided for. As healthcare professionals, we may need to provide structured educational programmes (in groups or one-to-one sessions) in order to achieve this. If we only follow the

existing guidelines, we are at risk of missing a significant percentage of people with diabetes who may not attend structured programmes.

While one individual felt relief at being given a diagnosis that legitimised why they were feeling so unwell, another described the information they received at the time of diagnosis as 'overwhelming'. The timing of education is, therefore, as important as the information being offered. At the initial point of diagnosis, the gap between appointments either needs to be shorter, or we need to offer open appointments so that people with diabetes can access support as and when they require it. Open-session appointments are currently being piloted in one of the author's nurse-led clinics.

There are several recognised structured education courses for people with type 1 and type 2 diabetes, for example DAFNE and DESMOND. Williams and Pickup (2005) report that there is a larger percentage of type 2 diabetes cases (approximately 85%) compared with type 1 (approximately 15%).

These courses are expensive for local trusts to implement in terms of staff training and teaching tools. As a result, local diabetes networks are increasingly exploring ways of delivering structured diabetes education in a more affordable way that still encompasses Government guidance.

The author's local diabetes network education sub-group is currently exploring ways of delivering structured education for people with type 2 diabetes in a more affordable way. The findings presented here have been shared with the diabetes network in order to assist in guiding their education programme structure, enabling it to more closely meet people with diabetes' individual needs.

Locally, there is a gap in structured education for people with type 1 diabetes. As a result of the present findings, the author and a dietetic colleague have jointly piloted a structured group education programme for people with type 1 diabetes that includes issues such as insulin titration

in relation to diet and exercise. The pilot education programme has been evaluated by people attending the programme and has been modified regularly to meet their perceived needs.

It is important that people with diabetes feel consulted and involved in their care, and the explanations offered to them are understandable. A patient-centred approach concentrating on what is important to the individual, rather than the healthcare professional's agenda, may be more effective in motivating lifestyle changes and may result in a positive health outcome. This view was explored by Knight et al (2006) who suggested that we need to challenge the current views on education and the relationship between people with diabetes and healthcare professionals.

Living with diabetes not only affects the individual but can also affect the family; some participants described interruptions to their social life around eating out with friends and family. Other respondents discovered that the whole family changed the way they ate as a result of the diagnosis. It is, therefore, important that family members are included in education, especially around dietary information, and should be invited to dietetic consultations with the person with diabetes.

Some individuals had made positive lifestyle changes including starting, or increasing, exercise, but some of the advice offered to respondents was perceived as basic. Owing to the risk of complications associated with diabetes, it is important that people with the condition are individually assessed prior to undertaking exercise for the first time. People with diabetes need guidance on where they can obtain this support; for example, existing links with sports programmes that offer health checks prior to starting an exercise programme.

Since the completion of this study, an additional patient representative has been appointed to the diabetes network task force. A dedicated specialist diabetes dietitian has also been appointed. The pilot structured

group education programme for people with type 1 diabetes has been completed and is currently being audited.

Conclusion

There is little doubt that effective diabetes education improves people with diabetes' quality of life and reduces the risk of diabetes complications. As healthcare professionals, we should work in an integrated way with our multidisciplinary team in order to deliver a high standard of both clinical care and appropriate, individualised educational programmes for people with diabetes. ■

Page points

1. It is important that people with diabetes feel consulted and involved in their care, and the explanations offered to them are understandable.
2. Living with diabetes not only affects the individual but can also affect the family; some participants described interruptions to their social life around eating out with friends and family.
3. Some individuals had made positive lifestyle changes including starting, or increasing, exercise, but some of the advice offered to respondents was perceived as basic.

DoH (2000) *Second Report of the UK National Screening Committee*. Available at: www.nsc.nhs.uk/pdfs/secondreport.pdf (accessed 14.02.2008)

Diabetes UK (2004) *Structured Care: Delivering better diabetes care*. Diabetes UK, London

Glaser B, Strauss A (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Transaction Publishers, New Jersey

Knight KM, Dornan T, Bundy C (2006) The diabetes educator: trying hard, but must concentrate more on behaviour. *Diabetic Medicine* **23**: 485–501

Watkins PJ, Amiel SA, Howell SL, Turner E (2003) *Diabetes and its Management*. Blackwell, Oxford

Williams G, Pickup J (1999) *Handbook of Diabetes*. Blackwell, London