

A picture of the impact of newly diagnosed type 2 diabetes

Joan Everett and David Kerr

ARTICLE POINTS

1 First Focus is an educational programme that aims to provide reassurance, support and education for people with newly diagnosed diabetes.

2 To ensure that this is effective, we need to have a full picture of the impact of the diagnosis of diabetes.

3 Quantitative data collected previously suggest that the aims of First Focus are being achieved.

4 A study undertaken to supply the qualitative data needed to complete the picture is described.

5 The information gained has given the diabetes team a greater insight and understanding of the experience of being diagnosed with diabetes.

KEY WORDS

- Diabetes
- Diagnosis
- Impact
- Focus groups

Joan Everett is Diabetes Specialist Nurse and David Kerr is Consultant Physician at the Royal Bournemouth Hospital, Bournemouth.

Introduction

If health professionals are to provide effective reassurance, support and education for people newly diagnosed with diabetes, they need to have a full picture of the impact of diagnosis. Quantitative data collected previously from patients on the First Focus education programme run by the Royal Bournemouth Hospital supply part of the picture. This article describes a study in which qualitative data were collected from patients who had completed the programme. The aim was to discover the subjective reality of the diagnosis and thereby complete the picture.

The Royal Bournemouth Hospital has operated a nurse-led, open-access education programme (First Focus) for people with newly diagnosed type 2 diabetes since April 1993. Quantitative data collected from participants in the programme demonstrate that it is effective, efficient and associated with a high level of patient compliance (Everett and Kerr, 1998). Full information about the First Focus programme can be found in the Spring issue of this Journal (Vol 2(1), pp 12-21).

However, the picture of patients' experiences following the diagnosis of type 2 diabetes is incomplete without knowledge of the subjective reality of the diagnosis for these individuals. Health professionals involved in the First Focus programme set out to complete the picture, by collecting qualitative information through semi-structured, group interviews.

Focus groups

Focus groups are becoming increasingly popular as a means of collecting qualitative information (Reed and Payton, 1997). Recent use has explored the role of the nurse practitioner (Torn and McNichol, 1998); Chinese populations in nursing research (Twinn, 1998); perceptions of diabetic severity (Dunning and Martin, 1997); clinical decision making (Bulmer, 1998); and informing nursing practice about AIDS (Nyamathi and Shuler, 1990).

A focus group comprises a group interview of people with a common interest. It centres

on a specific topic and is facilitated by a moderator. Qualitative data are generated by the group as they explore and clarify their views.

Advantages of the focus group

- Economical way of collecting information on the experiences of a number of people
- Encourages spontaneity because individuals interact with each other
- Provides a 'safe' environment as individuals need not respond to every question
- Individuals may benefit from the group support.

Disadvantages of the focus group

- Involves judgment from the moderator
- Responses may be influenced and changed by the group
- The group may be dominated by one person
- Some people may be inhibited by the group situation
- Transcription is more difficult than single interviews.

Aim of the study

A study was undertaken to discover the experiences of patients newly diagnosed with type 2 diabetes who had completed the First Focus education programme at the Royal Bournemouth Hospital.

Sample

Twenty people who had been diagnosed with type 2 diabetes within the previous

6 months and had completed the First Focus education programme were invited to attend the focus groups. Twelve people agreed to be interviewed in two groups. Their ages ranged from 51 to 78 years.

The interviews

The facilitator was a diabetes specialist nurse (DSN) at the Royal Bournemouth Hospital, but did not previously know the participants and had had no part in their education process. Ground rules were established and open-ended questions were asked; these proceeded from more general to specific questions, and involved all members of the group.

Data analysis

The focus group sessions were tape recorded; permission was obtained from all participants before commencement. The facilitator listened to the tapes several times to identify each person and accurately attribute all comments. The data were transcribed, coded and categorised.

Priorities and important themes were actively sought. Themes emerging from the first group were specifically discussed by the second group. The themes were:

- The length of time that participants had had symptoms of diabetes
- Previous knowledge or experience that participants brought with them, either consciously or subconsciously
- The impact of being told the diagnosis
- Appreciation of the nurse-led system
- Feelings of failure when dietary methods were unsuccessful
- Variations in primary care management.

Diagnosis

An open-access, nurse-led group session is held every Friday morning so that all people diagnosed with type 2 diabetes can be seen within one week of diagnosis. Patients arrive at this diagnosis by one of several routes: by attending their GP because of symptoms; through routine screening; or as the result of admission to hospital with another medical or surgical condition.

At least half of those in the focus groups had had symptoms of diabetes for the preceding 12–18 months and suspected

that they had diabetes. Typical comments included:

'I thought I had diabetes for about a year.'

'I went to the doctors with thrush; I had a pretty good idea it was diabetes.'

'I felt awful and had been ill for 18 months.'

'I've had the symptoms for about a year and felt generally unwell.'

The following comment from a middle-aged man was the exception, and he had begun to think there was some more sinister cause, such as cancer:

'I basically just did not know what was wrong with me — kept falling asleep when I came home from work, extremely tired, losing weight and passing lots of urine.'

Primary and secondary care use opportunistic screening to identify people with diabetes, and increasingly this is how patients are being diagnosed. These patients often have no symptoms of diabetes.

'Both me and the wife were tested — I had diabetes but she didn't.'

'I changed doctors, who took some tests.'

'I was diagnosed while having a heart operation.'

'I had severe pneumonia and was diagnosed when I was in hospital.'

Definition of diabetes

The groups were asked how they would have defined diabetes before being diagnosed. The most common associations were diet and injections.

'I thought I would have to prick my finger, take the pills and watch my diet.'

'I thought diabetes was sticking needles in your arms every day.'

'I must confess that I thought that if you were diabetic you had to give jabs everyday.'

'Watching what you eat and drink and don't eat sugar.'

These perceptions need to be explored early on so that correct information on healthy eating and the fact that the early use of insulin is not usually necessary can be properly explained. Patients cannot take any information on board if they are anticipating a first injection of insulin.

PAGE POINTS

1 At least half of the participants had had symptoms of diabetes for 12–18 months and suspected that they had diabetes.

2 Patients diagnosed by opportunistic screening in primary and secondary care often have no symptoms.

3 Before diagnosis, patients commonly associated diabetes with diet and injections.

4 Misconceptions about diabetes need to be explored early on and corrected.

PAGE POINTS

1 Everyone has some previous knowledge of diabetes, which they bring with them as baggage when they are diagnosed.

2 Myths and outdated knowledge need to be unpacked and expressed so that new information can be taken on board.

3 Being diagnosed with a chronic condition has been likened to a bereavement, with the loss of previous good health.

4 The diagnosis of diabetes affects not only the person concerned, but also wider family members.

Previous experience of diabetes

Everyone had some previous knowledge or experience of diabetes, which they brought with them, consciously or subconsciously, as baggage when they were diagnosed.

'My mother is 93, has diabetes, but does not finger prick — just takes a tablet a day.'

'My brother had it for 10 years.'

'My mother had diabetes, on insulin and I thought "Oh no! Have I got to go through all that?"'

'My father had diabetes and I remember a very different way he had to cope — lines and stuff, which drove him and the family mad.'

In order for the newly diagnosed person to accept the diagnosis of diabetes, myths and outdated knowledge need to be unpacked and expressed so that new information can be received and taken on board.

Impact of diagnosis

The groups were asked to recall their feelings when they were first diagnosed with diabetes.

'I've always kept well and it came as a shock to me that I had diabetes.'

'When I was diagnosed I thought "Oh my God, something else!"'

'Diabetes means intrusion — it intruded into my life.'

Being diagnosed with a chronic condition has been likened to a bereavement, with the loss of previous good health. The bereavement process of shock, guilt, anxiety/denial and anger/depression have to be worked through before acceptance is reached.

Impact on the family

The diagnosis of diabetes affects not only the individual, but also family members.

'Daughter was appalled by my diabetes.'

'When I was diagnosed, my daughter, sisters and brother all went off to be tested.'

'My daughter is a nurse who "pats me on the head" and my wife has become over-protective.'

When dealing with newly diagnosed patients, DSNs must also consider the needs of the wider family and how the

anxieties of family members may affect our patients.

About the First Focus programme

All of the participants were very appreciative of the First Focus programme and spoke highly of every aspect.

'Excellent programme — well thought out.'

'I was delighted to find a more relaxed approach to that my father had to suffer.'

'The plan of care was marvellous. Telephone calls were returned quickly and, on one occasion, fairly late into the evening.'

'The contact number was key and vital.'

People were asked specifically whether there was any aspect of the programme they did not like or how they thought the Focus programme could be improved. There were no comments from participants about this.

Group education

All of the education sessions are organised in groups, but each session is followed by individual appointments with the multi-disciplinary team members. The groups were asked their thoughts on this.

'Group sessions were very helpful and it was good also to talk to the nurse individually.'

'Education programme was excellent — good idea to have people as a group and to include partners as supporters.'

'The group was helpful and useful.'

'I was a bit apprehensive about attending a group, but was quickly reassured.'

Educating patients in groups is a cost-effective method, which can be less threatening than an individual consultation.

Nurse-led programme

When patients enter the First Focus programme it is explained that it is nurse led and that they will not see a hospital doctor for 3 months unless the nurse feels that it is necessary. The groups were asked to comment on this:

'Must have time to see if there are any changes.'

'Three months is a good time to see a doctor. I've already seen a dietitian to see how I'm doing.'

'I do not see any reason to have seen a

doctor earlier: all my questions and concerns have been answered.'

However, one person in the group did express concern:

'No disrespect to nurses as they do a wonderful job providing all the information, but it seemed an awfully long time before I saw a doctor.'

This person was concerned because, despite being started on medication according to our protocol, the medication was increased at his medical appointment.

When First Focus was set up in 1993, a protocol was developed whereby medication could be commenced at 6 weeks if necessary, according to weight and fasting blood glucose values. As with all protocols, this has been revised in the light of experience, variances and clinical judgment. In the new protocol, patients enter different pathways depending on their initial blood glucose level, symptoms and degree of ketonuria (Figure 1).

Gradual acceptance of diabetes

This theme was apparent throughout both focus groups. It takes time to come to terms with diabetes because of the implications, education required and lifestyle changes.

'I looked through the information several times. As you go forward you understand more, so I went back to it several times.'

'I read the information through two or three times because it was useful to keep and refer to it when necessary.'

'You slowly come to terms with diabetes.'

'You realise it is something you have for life, something that takes a period of time to absorb, not rushing everything through in 2 weeks.'

'I felt I slowly walked through the process.'

It is important to remember that the process of accepting diabetes is a gradual process. Patients have to work through a lot of emotions, as well as changing some aspects of their lifestyle.

PAGE POINTS

1 Patients entering First focus do not see a hospital doctor for 3 months, unless the nurse feels that it is necessary.

2 First Focus protocols have been revised in the light of experience.

3 Acceptance of diabetes is a gradual process: there are a lot of emotions to be worked through and lifestyle changes to be made.

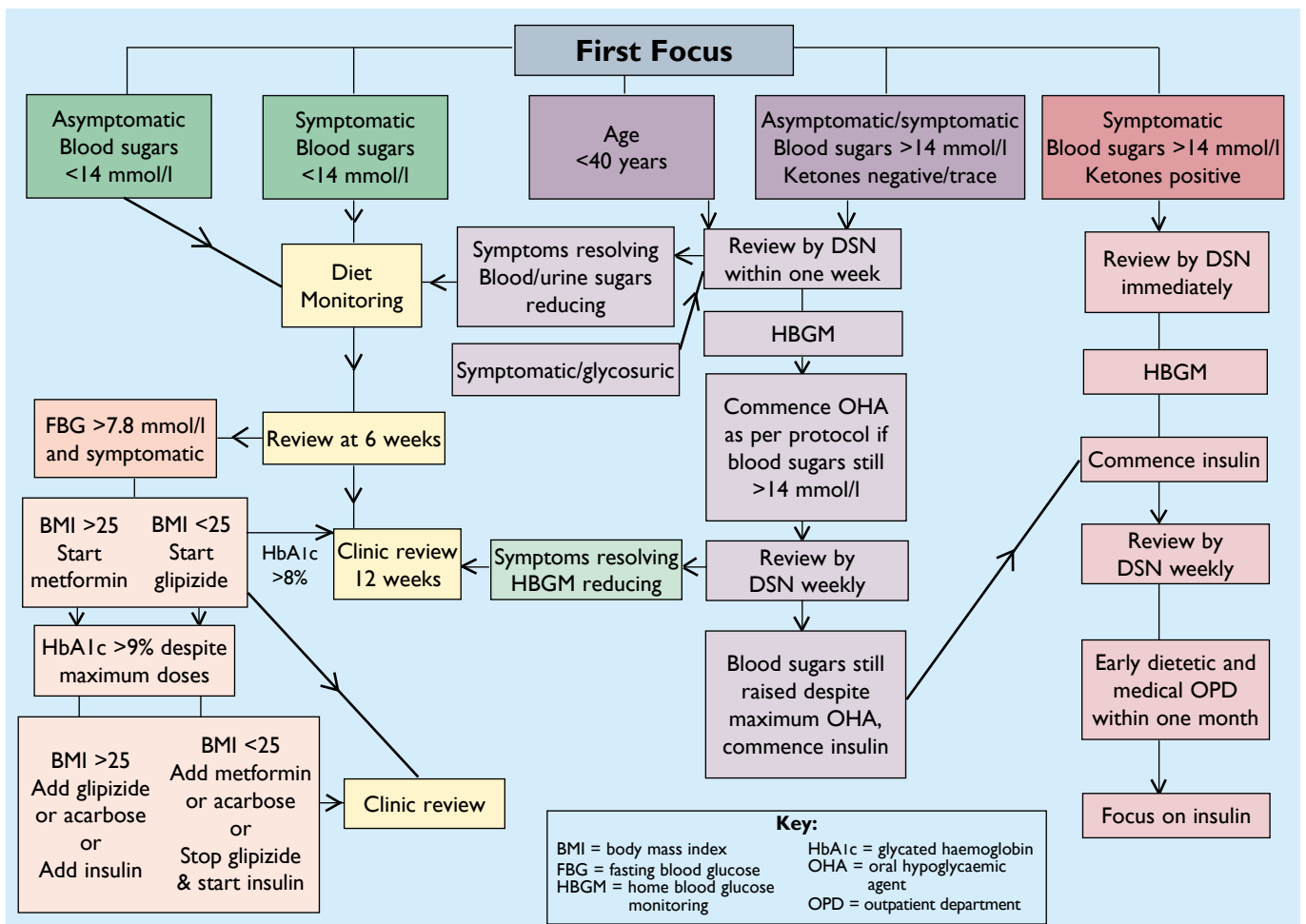


Figure 1. Protocol for management of newly diagnosed diabetes mellitus.

PAGE POINTS

1 Patients and diabetes nurses interpret 'control' in different ways.

2 Nurses talk about the diabetes being controlled, but patients think it is they themselves who are not in control.

3 After transferral to primary care, patients seemed to undergo different experiences, depending upon the system, experience and motivation of their local surgery.

4 Group education is not only cost effective, but also people seem to gain peer support from attending.

Taking medication

Some people did not like taking or increasing their medication because it made them feel that they had somehow failed and not gained the necessary control.

'I felt a failure at first when I was put on tablets; I thought I ought to be able to control it.'

'I was on diet for 2 months but it was not controlled, even though I lost weight and dieted. When she said I had to have tablets I thought "I'm not very good at this".'

'I wanted to keep on the diet longer. I was terribly upset to go on tablets. I hate taking tablets but it wasn't quick enough for them.'

Diabetes treated with tablets was seen as more serious than diet-controlled diabetes but less serious than taking insulin.

'If you are on diet it is less serious diabetes than tablets or insulin. It's up to you to control it when you are on diet, but if you are on tablets or insulin, other people control it'

'I did not realise you could take tablets for diabetes and it cannot be very bad if you take tablets not insulin.'

Diabetes seemed to be viewed as becoming more serious if medication was increased, because control had been lost. The word 'control' was mentioned many times.

'When I came to see the doctor I felt great, and when she put me on higher tablets I thought "I have not done this right because I am not controlled enough".'

'I tried to be careful but it was not any good. I was not controlling it. I needed more tablets.'

The link between starting medication and diabetes control seems to be misunderstood. Patients and DSNs interpret 'control' in different ways: nurses talk about the diabetes being controlled, but patients think it is they who are not in control. They feel that their need for medication indicates that they have 'lost control'. Starting medication clearly needs more explanation, with accompanying literature.

The education programme places much emphasis on controlling diabetes with a healthy lifestyle, and it seems that patients feel guilty when they cannot achieve this. Our new protocol places patients into different pathways on the

basis of diagnosis at First Focus (Figure 1). Patients most likely to require early medication are those who are symptomatic and have lower body mass. Patients in these groups could benefit from separate education, with more emphasis on the need for medication.

After the First Focus programme

Patients are usually transferred back to their GP at either 3 or 6 months. From this point, they seemed to undergo different experiences, depending upon the system, experience and motivation of their local surgery.

'The system here is perfect, but you miss the support'

'I am lucky because I have a diabetic doctor who deals with diabetes. He is very good and knows a lot about diabetes.'

'Now that I am back with my practice nurse, things are a bit cloudy. I know deep down that my tests are not good enough.'

'The hospital system is great, but it is afterwards — the system falls down afterwards as the GP is overworked.'

Discussion and implications for practice

The First Focus education programme was designed to provide reassurance, support and education for people with newly diagnosed diabetes. Comments from the focus group members seem to indicate that this has been achieved. It appears that many people have symptoms of diabetes for at least a year before diagnosis. The problem of earlier detection and diagnosis still needs to be addressed, in light of the complications detected at diagnosis (Matthews, 1998).

Patients receive a telephone call from the diabetes nurse 1–2 weeks after attending First Focus. Although the facilitator did not ask specific questions about this, it was mentioned spontaneously by patients in both groups. The call provides reassurance and evidence of caring. Although telephone calls are beginning to be recognised as valuable, traditionally they have not been counted as nursing workload.

Most people have family knowledge of diabetes that is outdated or mythical. This

needs to be explored and unpacked, and updated information given.

It is clear that the diagnosis of diabetes has a profound impact on both patients and family members. This anxiety needs to be addressed by including family members in the education programme.

Group education is not only cost effective, but also people seem to gain peer support from attending. One person described accepting the diagnosis of diabetes as a 'slow walk through diagnosis', which is obviously assisted by the planned programme.

One criticism of our First Focus programme has been that patients do not see the dietitian or hospital doctor soon enough. Participants' comments suggest that they feel that they see the dietitian at the right time. Certainly the dietitians say that by 2 months after diagnosis, people have had time to make any necessary changes and are ready to discuss long-term targets and goals. Most patients with newly diagnosed type 2 diabetes do not need to see a doctor earlier than 3 months, although there is a minority in whom earlier treatment needs to be initiated.

Reflections on the study

The interviews described here cannot be regarded as qualitative research, but should be seen as a reflection of the real-life experiences of a group of newly diagnosed patients. The information gained has given the diabetes team greater insight and understanding of patients' experiences, and has resulted in some changes in practice.

According to Bulmer (1998), the success or failure of focus groups rests upon the facilitator's ability to understand and manipulate the interpersonal dynamics within the group. No attempt to do this was made in this study, although the less vocal participants were specifically asked some direct questions to encourage all participants to take part.

Although the group was not previously known to the facilitator (JE), the interviews were held in the hospital diabetes centre and the facilitator was seen as a health professional despite taking great care not to influence the discussion, but to listen and ask appropriate questions.

No attempt was made to validate this study as the aim was simply to describe the experience of being newly diagnosed with diabetes in the local area. Previous attempts to determine patient satisfaction have resulted in completed tick boxes which give no insight into patients' real feelings. The data obtained in this study serve to increase awareness of what the patient newly diagnosed with type 2 diabetes has experienced. ■

Bulmer C (1998) Clinical decisions: defining meaning through focus groups. *Nursing Standard* **12**(20): 34–6
 Dunning P and Martin M (1997) Using focus groups to explore perceptions of diabetic severity. *Practical Diabetes* **14**(7): 185–8
 Everett J, Kerr D (1998) Nurse-led management of type 2 diabetes. *Journal of Diabetes Nursing* **2**(1): 12–21
 Holloway I, Wheeler S (1996) *Qualitative Research for Nurses*. Blackwell Science, Oxford
 Matthews DR, Cull CA, Stratton IM, Holman RR, Turner RC (1998) UKPDS 26: Sulphonylurea failure in non-insulin-dependent diabetic patients over six years. *Diabetic Medicine* **15**: 297–303
 Nyamathi A, Shuler P (1990) Focus group interview: a research technique for informed practice. *Journal of Advanced Nursing* **15**: 1281–8
 Reed J, Payton VR (1997) Focus groups: issues of analysis and interpretation. *Journal of Advanced Nursing* **26**: 765–71
 Sim J (1998) Collecting and analysing qualitative data: issues raised by the focus group. *Journal of Advanced Nursing* **28**(2): 345–52
 Torn A, McNichol E (1998) A qualitative study utilizing a focus group to explore the role and concept of the nurse practitioner. *Journal of Advanced Nursing* **27**: 1202–11.
 Twinn S (1998) An analysis of the effectiveness of focus groups as a method of qualitative data collection with Chinese populations in nursing research. *Journal of Advanced Nursing* **28**(3): 654–61

PAGE POINTS

1 It is clear that the diagnosis of diabetes has a profound impact on both patients and family members.

2 This anxiety needs to be addressed by including family members in the education programme.

3 One criticism of our First Focus programme has been that patients do not see the dietitian or hospital doctor soon enough.