

Designing an education programme for type 1 diabetes: A focus group study

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Research suggests that people with type 1 diabetes would benefit from an intervention that addressed their psychosocial needs as well as their practical needs, but such support is rarely available in the UK. This study used focus group discussions to explore what people with type 1 diabetes require from a programme of education and support by investigating their experiences of living with and managing this condition. This article describes the issues and themes that emerged from the data collected, their implications for practice and the development of a unique user-informed educational programme that supports the practical, emotional and psychological needs.

Research has shown that type 1 diabetes affects an individual's quality of life, particularly psychological wellbeing (Bradley and Gamsu, 1994; Cavan and Trigwell, 2003; Dose Adjustment for Normal Eating [DAFNE] Study Group, 2002). More recent studies have attempted to understand the experience of living with diabetes by focusing on psychosocial factors known to influence successful management.

The consensus appears to be that diabetes management is more than just the practicalities of diet, blood glucose monitoring and insulin – it is an evolving process to master a level of understanding regarding the impact that diabetes will have on the individual and his/her eventual acceptance of the condition (Richardson et al, 2001).

The person with diabetes also faces many challenges related to his/her process of normalisation, often accompanied by threats to

the self, the establishment and maintenance of a sense of control and dealing with the emotional impact of the condition (Paterson et al, 1999; Everett, 2001; Richardson et al, 2001; DeCoster, 2003). Everett (2001) suggests that while information and education provide some skills to develop and maintain an individual's sense of control regarding their diabetes management, psychological skills training is needed to ensure that control is available across all aspects of the individual's life.

Shearer et al (2004) suggest that all people with type 1 diabetes would benefit from an intense education programme such as DAFNE. Skinner (2003) takes this further by stating that education programmes should be 'interactive, structured and centred on the needs of the individual'.

To date, few UK-based education programmes have been developed in consultation with people with type 1 diabetes. Consequently, personal

Article points

1. Focus groups for people with type 1 diabetes explored their experiences of living with the condition and their education and support needs.
2. Eight themes emerged from the data analysis: mastery; control; stigma; deprivation; support; diagnosis; lifespan; health provision.
3. These were clustered into three categories: self-management; psychosocial factors; and interactions with health professionals or services.
4. This analysis informed the design of a unique programme of education and support for people with type 1 diabetes.

Key words

- Type 1 diabetes
- Psychosocial support
- Focus groups

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1. The study described here is relevant in that it explores the individual's perspective of what psychosocial support would help to improve his/her quality of life.
2. A total of 362 adults with type 1 diabetes were randomly selected from diabetes clinic lists and invited to participate.
3. Sixty people took part in the 10 focus groups, which ran during the summer of 2003.
4. Participants explained what it was like to live with diabetes every day. Subsequent questions arose from the conversation or were prompts to direct the group's talk.

experience of diabetes has not previously been acknowledged or incorporated into an education programme (Paterson et al, 1999; Mercado-Martinez and Ramos-Herrera, 2002).

This study was undertaken to explore what people with type 1 diabetes needed from a programme of education and support by investigating their own experiences of living with and managing this demanding condition. This article will describe the issues and themes that emerged from the data and their implications for practice, and the development of an intervention that supports their practical, emotional and psychological needs.

Methods

Design

In-depth, semi-structured focus group discussions were used to explore people's experiences of living with and managing type 1 diabetes. Focus groups can provide a supportive environment where participants feel able to talk about their experiences with one another (Skinner and Cradock, 2000; Funnell et al, 2005). The data collected represents people's attitudes about, perspectives on and stories of living with type 1 diabetes, and provides a valuable source of information about the support and education they wished to receive.

Inductive thematic analysis (ITA) was used to analyse the focus group transcripts. ITA offered a way of organising the data into categories that represent the meanings interpreted from sections of data (Wilkinson, 1998; Barbour and Kitzinger, 1999; Attride-Stirling, 2001). The data were examined by several researchers to ensure that the analysis was rigorous (Ely et al, 1991; Wilkinson, 1998; Barbour and Kitzinger, 1999).

Recruitment and sample

Following approval from ethical committees at North Bristol NHS Trust and the University of the West of England, adults with type 1 diabetes were recruited from clinic lists held in the diabetes departments of North Bristol NHS Trust. A total of 362 adults with type 1 diabetes were randomly selected and invited by letter to participate. As the intention was to gather

data in an exploratory manner, recruitment to focus groups ended once the analysts felt that saturation had been achieved and all the necessary information recorded (Ely et al, 1991; Hayes, 1997).

Sixty people (mean age 46.6 years \pm 12.3 years; mean duration of diabetes 21.0 years \pm 12.0 years; 63.3% were women) took part in 10 focus groups, which ran during the summer of 2003. A breakdown of the participants' characteristics is given in *Table 1*.

The focus groups

Focus groups were run at local community centres and lasted between 1.5 and 2 hours. All were recorded and transcribed verbatim. The researcher asked participants to explain what it was like to live with diabetes every day. Subsequent questions either arose from the conversation, were prompts by the researcher to direct the group's talk, or to focus on a specific issue, such as management needs and interactions with health professionals (Hayes, 1997; Attride-Stirling, 2001). The amount of questioning required varied between groups. All data were anonymised.

Data handling and analysis

The analysts were the two researchers who had been at the focus groups and a DSN with 16 years' experience of working with people with type 1 diabetes. Each transcript was carefully examined by at least two analysts and each interpretation was cross-checked to ensure parity between interpretations. For the final analysis, several meetings were held where categories and themes were compared and discussed (Ely et al, 1991; Krueger, 1994).

Analysis began with open coding of transcripts to allow the researchers to identify areas of relevance emerging from the data; these formed the basic themes. Themes were then clustered to form categories. Each category captures the primary supposition of a cluster of themes (Wilkinson, 1998). Categories were examined in relation to the story they told about the themes that formed them (*Figure 1*) and exemplars of data used to illustrate and explain their meaning (Wilkinson, 1998; Attride-Stirling,

Table 1. Characteristics of the focus group participants

	Total	Age (years)						Duration of living with diabetes (years)				
		20–30	31–40	41–50	51–60	61–70	71–80	0–10	11–20	21–30	31–40	41–50
Male	22	1	7	4	6	2	2	4	2	10	5	1
Female	38	2	11	11	8	6	0	13	10	10	4	1

2001).

A summary of each theme, with quotes, and a programme exemplar was presented to all participants either by post or at three informal feedback sessions. The revised components of the resulting educational programme are presented in Table 2.

Results

Data analysis identified eight themes: mastery, control, stigma, deprivation, support, diagnosis, lifespan, healthcare/health professionals. These themes were clustered into three overarching categories: self-management; psychosocial issues; and interactions with health professionals/clinical services (Figure 2).

Self-management

Focus group conversation coded with the themes in this category centred on the practical aspects of living with diabetes. These themes emerged when people talked about the factors that impact on their ability to control their diabetes day-to-day; how they integrated it (or not) into their lives; and the temporal and dynamic nature of diabetes.

Control

Day-to-day control of diabetes was implicit to participants' lives and encompassed control of food, activities and, most importantly, blood glucose. For example, participants often talked about the need for strict control of their blood glucose as an immediate and at times overwhelming necessity:

'...checking everything ... if you go anywhere you have to make sure you've got your [insulin] pens – you're carrying all this rubbish with you.'

(man, age 23, lived with diabetes for 5 years)

'...it's not the sort of thing that you can say

"tomorrow my blood sugar is going to be xyz so I'm going to eat this or not eat that".

Really, you're playing by the minute.'

(woman, age 54, lived with diabetes for 45 years)

Mastery

Mastery described participants' need to have complete control over their diabetes so that they were able to prevent diabetes dominating their lives. It was not simply about being in day-to-day control of diabetes, but also about possessing the ability to manage effectively all or most of the difficulties associated with living with diabetes. The conversation that characterised this theme expressed mastery as either something that had been achieved or whose achievement was desired:

'You accept it and you get on with life or you don't. Simple as that. No room for self pity or anything like that; you just accept that you have it, you have to put up with it...'

(man, age 71 years, had lived with diabetes for 40 years)

Lifespan

Participants also talked about the demands that the different phases of life present and the ways in which that impacted on the management of their diabetes.

'I've actually found it harder as time's gone on, from being diagnosed at like 7, well 7 and a half, and I'm now 34. I had my rocky period when I was like 14, 15...'

(woman, age 34, lived with diabetes for 27 years)

Psychosocial factors

Conversation that fell into these themes dealt with how participants negotiated the management of their diabetes alongside the opinions and attitudes

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1. Eight themes, clustered into three categories, were identified.
2. In the self-management category, control, mastery and lifespan were found to be the emerging themes

Page points

1. Many participants felt deprived of the dietary and lifestyle freedoms that people without diabetes enjoyed, and wished to be 'normal' and non-diabetic.
2. Although participants valued support from their families, there was a clear desire to be supported in a way that enabled and empowered them to manage their diabetes themselves.
3. Support that was seen to be intrusive or controlling was also felt to be counter-productive.
4. The way in which diagnosis and related events were managed by health professionals at the time seemed to have a significant and enduring impact on their perception of their future.
5. Many comments about healthcare provision were negative.

of others and the sense of deprivation and stigma that this can create. The support provided by their family, peers and health professionals was instrumental in either moderating or exacerbating the impact of living with type 1 diabetes.

Stigma

One of the most contentious issues for most participants was the image that having diabetes projects and the stigma that results from that. They felt that they were defined by their diabetes and that it had a negative impact on the way that others interacted with them. This was often seen to be most problematic in their relationships with health professionals:

'You are "a diabetic" in their eyes, you know, so you're not just a person who's not feeling well. So yeah, they do put you in the little box of diabetes...'

(man, age 65, lived with diabetes for 26 years)

Deprivation

Many participants talked about being deprived of the dietary and lifestyle freedoms that people without diabetes enjoyed.

'...just the freedom...just for the freedom. And you see other people and think, oh, you've just been and bought that cake and they've come out eating it, you know...'

(woman, age 49, lived with diabetes for 7 years)

This was inextricably linked to their desire to be 'normal' and non-diabetic:

'I just mean I don't want to inject, I don't want to do anything, I just want 6 weeks. I don't want to come in here, I don't want to see a doctor, I don't want to be ill, I just want 6 weeks off.'

(woman, age 44, lived with diabetes for 34 years)

Support

Participants also talked about needing and valuing support from their families. However, there was a clear desire to be supported in a

way that was not intrusive and enabled and empowered them to manage their diabetes themselves. Support that was seen to be intrusive or controlling was also felt to be counterproductive:

'...with my family, I think they're totally uneducated on diabetes. They seem to think "Oh, you can't have sugar things" but that's totally wrong; you've got to have some sugar level...'

(woman, age 44, lived with diabetes for 18 years)

Interactions with health professionals and clinical services

Participants talked openly about healthcare provision, clinic visits, prescription systems and the need for regular updates regarding recent developments and recommended changes in diabetes management. However, it was the interactions they had with health professionals and the clinical care experienced that had a significant impact on their lives. Specifically, the way in which diagnosis and related events were managed by health professionals at the time seemed to have a significant and enduring impact on their perception of their future.

'I was diagnosed at the age of 24...and I thought that's it, I'm not going to get married, I'm not going to have children...'

(woman, age 50, lived with diabetes for 26 years)

It also affected the way that participants talked about their subsequent management of their diabetes and interactions with health professionals. For example:

'...you know no one ever sort of said well this'll happen, that'll happen. I do remember [someone] said you ought to get between 15 and 20 good years...I well remember those famous words. And I keep thinking to myself, well I haven't done bad.'

(man, age 71, lived with diabetes for 40 years)

Many comments about healthcare provision were negative and suggested that some of their relationships with health professionals were punitive. For example:

'He did not trust diabetics. They expect you to be bad. If your blood sugars are bad, it's your problem...'

(man, age 39, had lived with diabetes for 23 years)

'...they're saying "oh, if your not going to do this, I will take you down to the amputation ward" and [they] frighten you like that.'

(woman, age 33, lived with diabetes for 23 years)

These experiences indicate a need for health professionals to acknowledge the impact that diabetes has on the individual and for them to develop a greater understanding of what living with diabetes is like. However, participants commented that this varied across and within professional groups, suggesting the need for consistency in the information provided and the way in which it is provided.

'...this dietitian told me [something] totally different to what...our doctors did...I think each one is different.'

(woman, age 38, lived with diabetes for 27 years)

'... definitely the diabetic nurse has been a great help ... I can phone her whenever I like, and she's always – doesn't matter whether I've seen her 6 months ago or yesterday – she always really sort of sounds pleased to hear from you and is open to listening and very helpful.'

(woman, age 47, lived with diabetes for 18 years)

Participants often felt awkward in asking for information and clarity, not wanting to waste any more time. These experiences indicate a need for patients to develop their assertiveness skills during the consultation process, with the

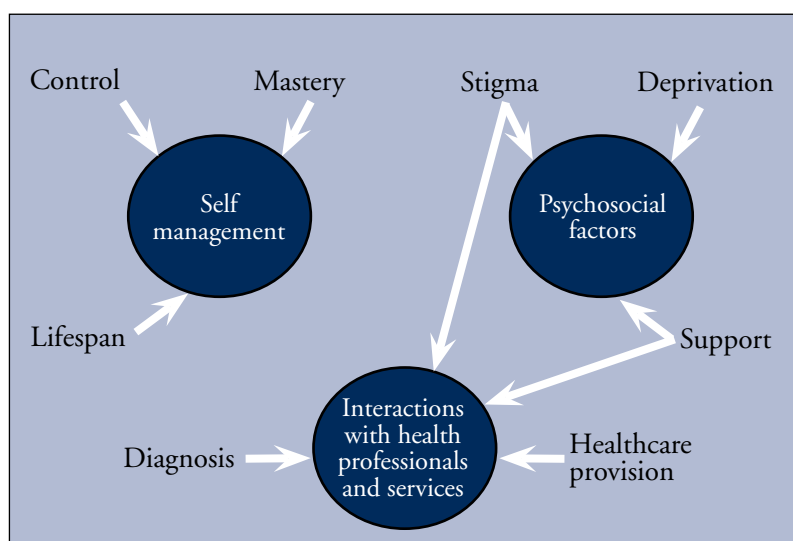


Figure 1. Triangulation of data.

Table 2. Relationship between the themes and the programme components

Components of the programme	Themes
<i>Healthcare worker responsible for the session</i>	
Example of Jane: a hypothetical woman who has been diagnosed with diabetes <i>Psychologist and DSN</i>	Diagnosis; Lifespan; Control; Deprivation
Risks and finding the balance in living with diabetes <i>Psychologist and DSN</i>	Control; Mastery; Deprivation
Myths and fears: the things that people worry about and are not sure about <i>Psychologist</i>	Control; Mastery; Deprivation
Diet and alcohol: based on DAFNE model <i>Dietitian</i>	Control; Mastery; Deprivation; Health care and health professionals
Hypos: the mechanism of hypos and how to manage them <i>DSN</i>	Control; Mastery; Deprivation
Weight, self-image and assertiveness <i>Psychologist and DSN</i>	Stigma; Control; Mastery; Deprivation; Health care and health professionals
Cognitive coping: strategies for reducing and dealing with feelings <i>Psychologist</i>	Lifespan; Support; Deprivation; Stigma; Control; Mastery
Family matters <i>Psychologist and DSN</i>	Support; Stigma; Control; Mastery; Lifespan; Deprivation
Stress and relaxation <i>Psychologist and DSN</i>	Control; Mastery; Support; Lifespan
Flexibility on managing diabetes <i>DSN</i>	Control; Mastery; Deprivation; Stigma
Making the most of consultations <i>Psychologist and DSN</i>	Health care and health professionals; Support; Control; Mastery

Page points

1. It is clear that people with type 1 diabetes need to be able to manage stigma, deprivation, and fears regarding complications, and to improve their relationships with health professionals
2. This study emphasises the need for health professionals to make use of the experiences and knowledge of those with diabetes to ensure that management protocols and education programmes are relevant and appropriate.
3. The intervention is intended to empower and enable people to make positive changes to the way they manage their diabetes.

aim of improving patient satisfaction and self-care management.

Discussion

Detailed examination of the data from this study indicates that addressing the biomedical and practical needs of people with type 1 diabetes is essential and this should include their concerns about achieving and maintaining blood glucose control, guidance on managing hypoglycaemic episodes, and calculating carbohydrate and insulin ratios (Stewart and Shamsodani, 1990; Waterton and Wynne, 1999). However, it became clear that it is also important to enable people with type 1 diabetes to develop skills to manage issues of stigma, deprivation, fears regarding complications and to improve confidence in relationships with health professionals (Plank et al, 2004). This requires training in cognitive-behavioural techniques, including assertiveness, stress management and goal setting (Cavan and Trigwell, 2003; Dusseldorp et al, 1999).

An intervention for people with type 1 diabetes should therefore address educational, psychosocial and support needs. Data collected from the focus groups and ongoing collaborative discussions with people with type 1 diabetes has informed the design of an intervention (Table 2) and the philosophy underpinning this programme is one of co-operation, interaction and shared learning. It is intended to empower and enable people to make positive changes to the way they manage their diabetes. Detailed in a study to be published elsewhere, the authors have piloted this bespoke user-informed intervention and examined its impact on glycaemic control, psychological wellbeing, diabetes-specific knowledge and quality of life.

The study presented here emphasises the need for health professionals to make use of the experiences and knowledge of those with diabetes to ensure that management protocols and education programmes are relevant and appropriate (DH, 2001; Glasgow et al, 2002).

There are some limitations to this study. The use of ITA to analyse the data meant that the interactions between participants and

the ways in which shared accounts of living with type 1 diabetes were negotiated were not examined (Green and Hart, 1999), in that the development of the themes was based upon the talk that was apparent and not on the way that it emerged during conversation (Roulston, 2001). Nonetheless, the conversations that evolved were examined in context and the aims of the research were met. It is also likely that the people who participated in the study were articulate, motivated and interested, which suggests that there was already a bias and that some views and opinions remained unheard (Duggleby, 2005; Funnell et al, 2005; Kidd and Parshall, 2000). ■

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