

Patients' perspectives on diabetes health care education

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Abstract

Living with Type 2 diabetes requires that patients develop a range of competencies that allow them to take greater control over the treatment of their disease. This requires education that promotes health whilst respecting individuals' self-perceived needs and voluntary choices. Whilst such a concept is not new in the field of diabetes, health professionals are still struggling with how to administer it successfully. This paper presents the findings of a research trial of a theoretically constructed educational intervention. It focuses on the patients' perspectives of what they valued about the intervention which was found to be clinically effective over a short-term period only. Limitations to maintaining effects were associated with a number of factors. The study found that whilst patients can be educated toward greater autonomy, not all health professionals are ready to work in partnership with them. It highlighted the importance of clinical staff not only gaining a better understanding of diabetes management, but also of the theoretical principles underlying patient empowerment. This paper outlines these principles and shows how they were synthesized to produce a framework for informing practice.

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Patients' views are utilized to provide guidelines for improving the outcomes of patient education.

Introduction

With the increasing public health burden of chronic diseases has come universal recognition of the need to manage them more effectively. Davis *et al.* identify a range of generic strategies that can be applied to chronic disease management (Davis *et al.*, 2000). These include education with the explicit aim of enhancing active involvement of patients so that they become partners in their health care process. Such a model has arisen with realization that patients are both the producers of health and the customers of health care (Holman and Lorig, 2000). This highlights the active role that patients need to play, and calls into question the relationships between health professionals and patients. Silverman argues that power relations between patients and health professionals are only really challenged when patients with chronic illnesses 'know the ropes' so that they become more active, resourceful and prepared to question medical judgement (Silverman, 1987). This is an explicit ingredient of the concept of patient empowerment which Tones believes is central to all health education activities (Tones, 1991). In this paper we consider empowerment in relation to diabetes patient education, discuss its application and what patients perceived to be important for promoting long-term benefit.

The control of diabetes is complex, made up of a number of separate treatments with education representing a single facet within this package. Mulrow and Pugh pointed out that although treat-

ments aimed at certain facets of complex interventions may be more efficacious than others, interventions aimed at single parts of a complicated treatment cannot be expected to be highly efficacious (Mulrow and Pugh, 1995). This highlights the interdependence of diabetes management strategies which centre around three key elements:

- Education and support for self-management (including reduction of lifestyle risk factors).
- Effective drug treatment strategies for maintaining normal blood glucose and lipid levels, and normal blood pressure.
- Effective surveillance for early detection and treatment of complications.

Inclusion of these three elements requires a sequential phased approach to address the evaluation of the various interconnecting parts. These phases have been defined by Campbell *et al.* (Campbell *et al.*, 2000) as part of a strategic Medical Research Council paper (www.mrc.ac.uk/txt/pdf-mrc_cpr.pdf), and show that the evaluation of patient education requires access to theoretically developed and evidence-based training programmes.

A review of patient education research was therefore undertaken to explore its effects, the means by which such effects had transpired, implications for educational treatment and the gaps that exist in current research practice (Cooper *et al.*, 2001). Twelve meta-analyses, reporting the cumulative effects of 565 independent trials, were identified concerning education for people with chronic diseases where behaviour modification is a part of the treatment regime. By combining the results of these meta-analyses, a second-stage descriptive meta-analysis was conducted. The results showed that trials had failed to use theory to guide intervention design and outcome evaluation, and few studies had looked at the processes by which outcomes had transpired, adhering predominantly to quantitative research traditions. Given this evidence, we undertook to overcome the gaps identified by researching the effects of a theoretically constructed empowering education programme.

Methodology

Applying theory to practice

Kurtz argued that diabetes must be operationally defined in terms of the many specific behaviours it subsumes (Kurtz, 1990). From this perspective, he concluded that models predicting behaviour change should not be used alone where diabetes treatment is concerned, but should be used simultaneously. Other studies have reached similar conclusions recommending that where complex behaviours are concerned researchers should systematically integrate available theories and models to see when they can be used jointly (Rogers and Brawley, 1993; AbuSabbah and Achterberg, 1997).

For this study, a comparison was made between the theories associated with adult experiential learning (Table I) and health protective behaviour (Table II). This produced a framework of variables that could be used to direct practice (how to do it), intervention goals (what to achieve) and what might explain any outcomes of the intervention (Cooper, 2001). These variables differed in combination but were common to all the theories, and included (1) cognitive factors, i.e. attitudes and self-related beliefs including perceptions of self-efficacy, and (2) social–environmental variables such as social norms, influences of friends, family and health care providers. Emotional responses to illness were not present in the theories as they are orientated toward prediction of health behaviours in ‘well’ people. The theory of personal models of illness was therefore also included. This is concerned with the study of mental representations of illness and fits more closely with a concept of illness-behaviour as a response to the problematic experience of illness. Weinman and Petrie (Weinman and Petrie, 1997) argue that such illness perceptions have become more important as the emphasis of health care moves toward prevention of disease in healthy populations and on improving rates of adherence to treatment programmes in those with chronic conditions. These changes have increasingly challenged the established view of the patient as a passive participant in the health care

Table I. Brief comparative summary of the theories associated with adult learning which were used to direct the research trial

Theory	Cognitive	Behaviourist	Humanist
Description	<ul style="list-style-type: none"> ● knowledge/skills: link prior knowledge/experiences with new information ● attitudes: formulate new ideas through process of deduction ● understanding: insightful learning gained through adaptation of existing knowledge or past experiences to form new insights 	<ul style="list-style-type: none"> ● behaviour learnt by making a link between a stimulus and a response (conditioned responses) ● development of self-efficacy which removes doubts about abilities to modify behaviour ● learning achieved through repetition of successful actions (trial-and-error learning—operant conditioning, copying others' behaviours—vicarious conditioning) 	<ul style="list-style-type: none"> ● higher cognitive needs met by understanding the psychological factors influencing behaviour ● development of awareness and understanding of attitudes toward certain situations ● insightful learning gained through understanding personal feelings to certain situations
Application for learner	<ul style="list-style-type: none"> ● learning seen as a process of thinking, perception, organization and insight; associated with problem-solving approaches to learning 	<ul style="list-style-type: none"> ● development of understanding of how emotional responses are related to certain situations; associated with education and counselling to extinguish established fear/anxiety responses and behaviour modification 	<ul style="list-style-type: none"> ● confrontation of personal problems to gain insight into emotional responses; associated with patient education to facilitate understanding of the emotional aspects of learning to live with a chronic disease
Application for teacher	<ul style="list-style-type: none"> ● need to make new information meaningful to learners by linking it to that already known 	<ul style="list-style-type: none"> ● need to use reinforcement—positively to reinforce behaviour, negatively to prevent repetition of behaviour; behaviour of teacher provides a model for learners to copy 	<ul style="list-style-type: none"> ● need to show integrity, respect and compassion toward learners

process so that illness representations have become more pertinent.

Consistencies between the theories of adult education and health protective behaviour therefore lie in their focus on learning as a continuous process grounded in experience, and which takes into account the role of emotional feelings and choice, alongside cognition. This aligns patient education to an experiential learning process within which beliefs about self-efficacy and the effects of social–environmental influences are central to outcomes. Bandura has defined self-efficacy as the ‘belief in one’s capabilities to organize and execute the sources of action required to manage prospective situations’ (Bandura, 1982). This proposes that individuals will undertake certain behaviour changes only if there is a belief in them being successful and, as such, it is an important goal in health promotion activities. It highlights the

relevance of education aimed at affecting changes not just in behaviour, but also in knowledge, skills, understanding and/or attitudes which, in turn, may manifest themselves as changes in clinical (physiological) measures.

This suggests a hierarchy of outcomes and has implications for the way in which patients are supported when trying to reinforce positive behaviours. From this perspective outcomes other than just physiological measures need to be rewarded if changes are to be encouraged and maintained. Such a view is emphasized by Tones and Tilford in their definition of health education which appropriately amalgamates the theoretical and practical constructs so far described (Tones and Tilford, 1994):

Health education is any intentional activity which is designed to achieve health or illness

Table II. Brief comparative summary of the theories associated with health protective behaviour which were used to direct the research trial

Concept	Expectancy value models		Process-orientated model			
	Theory of planned behaviour		Personal models of illness			
Description	Stages of change		patients' perceptions of:			
	● external variables	e.g. knowledge, locus of control, anxiety	● pre-contemplation	● identity	disease label and symptoms	
	● attitudes	toward adopting a behaviour	● contemplation	● considering change but no commitment to change	● time-line	temporal course of disease
	● subjective norms	beliefs about how significant others feel about behaviour and motivation to comply with their requests	● preparation action	● intention to change in the process of changing behaviour	● consequences	effects of the disease
	● perceived behavioural control	perceived ability to exert volitional control over behaviour	● maintenance	● an extended period with emphasis on preventing relapse	● cause	degree of personal responsibility
Self-related beliefs	● perceived behavioural control (self-efficacy)	● self-efficacy	● relapse	integral part of the change process; may occur at any level	● cure	acute diseases
	–	● perceived behavioural control	● existing harm of current behaviour		● treatment/control	chronic diseases
Illness-related beliefs	–	● self-efficacy	● existing harm of current behaviour		● perceived personal control (self-efficacy)	
		● behavioural expectations, outcome evaluations	● pros and cons of behaviours		● personal responsibility for 'causing' disease, seriousness of disease, likelihood of complications	
Behavioural beliefs and attitudes	● behavioural expectations, outcome evaluations	● pros and cons of behaviours			● effectiveness of treatment (outcome evaluations)	
Social environmental	● social norms (normative expectations), outcome evaluations	● social support, outcome evaluations			● impact on personal lifestyle	
Mediating variables	● behavioural intention	● relapse			● emotional response to disease	

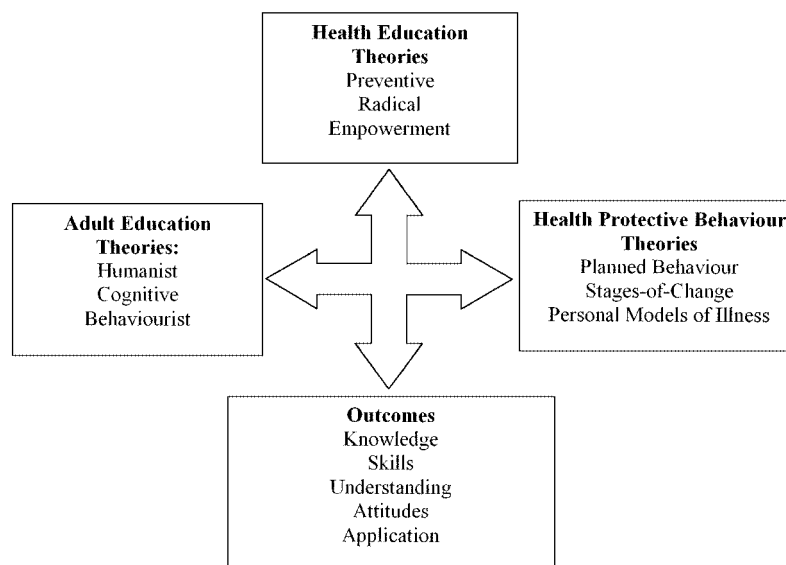


Fig. 1. Integrated model showing the theoretical base and outcome variables for diabetes patient education.

related learning, i.e. some relatively permanent change in an individual's capability or disposition. Effective health education may thus produce changes in knowledge and understanding on ways of thinking; it may influence or clarify values; it may bring about some shift in belief or attitude; it may facilitate the acquisition of skills; it may even effect changes in behaviour or lifestyle.

This definition illustrates how the theories described inter-relate to produce a working model for patient education, as shown in Figure 1. It illustrates how the various theories focus on five domains of learning in which change may take place: knowledge, skills, understanding, attitudes and application. This model was used as the framework for directing patient education (process) and intervention goals (outcomes) within the trial.

Research design

A randomized controlled wait-list trial was conducted, whereby allocation to treatment was staggered over a period of 14 months with five trial courses running over a period of 1 year. Participants were blindly and randomly allocated to the inter-

vention at 0 months (short-term trial group) and at 6 months (short-term control group); after which the short-term groups were combined to form the long-term trial group, to be compared with those allocated to the course after 12 months (long-term control group). This method overcame the ethical limitations of excluding patients from educational treatment, and permitted collection of data over a short- and long-term period. The trial was designed to address the following questions. Would participation in the intervention:

- Have an impact upon patients' illness beliefs?
- Lead to changes in self-care behaviours?
- Have an impact upon blood glucose control?

Sample size

Using the results of eight pilot courses, a total sample size of 48 patients was found to be required to achieve a 1% change in blood glucose levels (as measured using HbA_{1c} blood test). A total of 89 patients with Type 2 diabetes were actually recruited, but this represented only 40% of the total number of people asked to take part. Main reasons for refusal included lack of interest in taking part in the research and lack of time. The need for patients to commit themselves to an

Table III. Demographic, medical and social characteristics of long-term trial and control group participants

Characteristics	Trial group (n = 53) [% (n)]	Control group (n = 36) [% (n)]
Mean age (years)	58 (range 30–70)	58 (range 35–73)
Male:female	57 (30):43 (23)	58 (21):42 (15)
Ethnicity (other than Caucasian)	2 (1)	0 (0)
Employed	25 (13)	39 (14)
Unemployed	44 (23)	39 (14)
Retired	31 (16)	22 (8)
Desirable weight (BMI <25)	8 (4)	6 (2)
Current smokers	21 (11)	22 (8)
Alcohol intake (above safe limits)	8 (4)	17 (6)
Living alone	21 (11)	11 (4)
Management of diabetes		
shared care (hospital and GP)	85 (45)	78 (28)
GP care only	15 (8)	22 (8)
Mean time since diagnosis (years)	6 (range 1–28)	6 (range 1–30)
HbA _{1c} levels [mean (SD)]	7.9 (1.7) (range 4.5–11.0)	7.0 (1.6) (range 4.6–10.6)
Treatment		
no drugs (diet controlled)	25 (13)	34 (12)
biguanides	56 (29)	37 (13)
sulfonylureas	40 (21)	37 (13)
other (acarbose)	4 (2)	0 (0)
combination	23 (12)	20 (7)
Co-morbidities (diagnosed)		
hypertension	51 (27)	47 (17)
hyperlipidaemia	28 (15)	22 (8)
ischaemic heart disease	25 (13)	8 (3)
cerebral vascular disease	2 (1)	3 (1)
retinopathy/cataract	13 (7)	8 (3)
neuropathy	19 (10)	3 (1)
microalbuminuria	0 (0)	6 (2)

8-week educational programme may well have affected recruitment. Characteristics of the people who refused to take part were analysed in relation to age, ethnicity and sex ratio, and showed no difference to those recruited.

A summary of participants' characteristics is provided in Table III. Overall, they were comparable in relation to their demographic, medical and social characteristics. Significant differences were encountered for co-morbidities only (χ^2 , $P = 0.02$).

The educational intervention

The intervention chosen was based on the Health Education Authority's 'Look After Yourself' programme. Central to its philosophy was an empowerment approach to health education and as

such it was based on the premise that the acquisition of knowledge is not sufficient to equip the individual for self-directed action. It stressed that knowledge needed to be combined with motivation and a range of skills (practical, physical, conceptual, emotional, social and personal) in order to promote action. The Diabetes Look After Yourself (DLAY) intervention comprised 8 weekly sessions, each lasting approximately 2 h, delivered by tutors who were all diabetes specialist nurses, and who were trained together and provided with a teaching manual to ensure standardization of content (Cooper, 1994). Course content included exercise and relaxation training and a variety of health topics relating to diabetes self-management. The format of the course was largely interactive using

Table IV. *DLAY intervention: workshop content*

	Week							
	1	2	3	4	5	6	7	8
Exercise and relaxation training	✓	✓	✓	✓	✓	✓	✓	✓
<i>Health topics</i>								
Introduction to course: personal experiences of Type 2 diabetes	✓							
Nutrition		✓	✓					
Physical activity & exercise				✓				
Exploration of feelings about having diabetes					✓	✓		
Making lifestyle changes		✓	✓	✓	✓	✓		
Self-monitoring		✓	✓	✓	✓	✓	✓	✓
Screening							✓	
Reducing the risks of complications							✓	
Working with health care professionals								✓
Making an action plan and treatment decisions	✓	✓	✓	✓	✓	✓	✓	✓

specially designed work sheets, problem-based learning, small and large group discussions, goal setting, skills training, and self-reflection. It was underpinned by experiential learning so that participants were recognized as having personal expertise in the management of their diabetes, whilst group processes were used to encourage changes in beliefs and values about diabetes. In this way it linked into the theoretical foundations of health education, adult learning and health protective behaviours. The relaxation component was seen as incremental to other parts of the course that dealt with participants' feelings about being diagnosed with diabetes and fears of complications. In this way the intervention addressed a 'grey area' of diabetes which education programmes have tended not to address in the past (Zettler, 1995). A summary of the course is outlined in Table IV and illustrates what a typical 'intervention' patient would have experienced. Resources required for each course included:

- Training programme for health care professionals (11 day taught course, now reduced to 6 days + home study).
- Staff time to facilitate course including prepara-

tion time (approximately 20 h×1 nurse + 5 h×1 dietician).

- Teaching equipment including flip charts, paper, pens, photocopied handouts.
- Refreshments.

Results

Clinical findings

This paper focuses on the patients' perspectives of what they valued about the intervention and is therefore primarily concerned with the qualitative outcomes of the trial. A summary of the quantitative clinical results is provided in Table V. At 6 months, the trial participants showed significant differences to the control group in their blood glucose control (logistic regression, $P = 0.005$), but not at 12 months ($P = 0.84$). Significant differences between the groups were found for changes in attitudes towards diabetes at 6 months (unpaired t -tests, $P = 0.04$) and at 12 months ($P = 0.01$). Significant differences were also noted for changes in perceptions of self care treatment effectiveness at 6 months (Mann-Whitney U -test, $P = 0.02$), but not at 12 months ($P = 0.23$). Positive improvements in diet and exercise behaviour for both groups were noted, with the trial groups making greater changes than the control groups, but these did not reach significance. Wide variations around the means were noted for both groups in relation to these behaviours. Significant differences between the groups for changes in self-monitoring behaviours were noted at 12 months (χ^2 , $P = 0.002$), but not at 6 months (0.21).

Patients' perspectives

In addition to the quantitative measures, qualitative methods were utilized in the evaluation. These included 10 focus group interviews (five immediately after the courses and five at the end of the trial) using a semi-structured tool to explore patients' perceptions of the intervention and its effects. No sampling and selection strategy was required for these interviews because participants were already established into groups. These groups were considered to be homogenous with regard to

Table V. Clinical results for selected variables

Study variables	Short-term baseline values		6 months scores		P^a	Long-term baseline values		12 months scores		P^a
	Trial	Control	Trial	Control		Trial	Control	Trial	Control	
Blood glucose control (HbA _{1c}) (normal range 4–6%, ↓ = better)	7.8 (1.7)	7.3 (1.6)	7.7 (1.6)	8.0 (1.7)	$P = 0.005^*$	7.9 (1.7)	7.0 (1.6)	7.9 (2.1)	7.2 (1.6)	$P = 0.84$
Attitudes ^b (scale: 0–100%, ↑ = better)	72.8 (13.2)	76.7 (14.2)	74.9 (11.7)	73.4 (9.5)	$P = 0.04^*$	73.1 (11.9)	74.6 (11.0)	75.1 (11.0)	70.5 (11.0)	$P = 0.01^*$
Treatment effectiveness ^c (Likert scale 0–5, ↑ = better)	4.3	4.1	4.6	4.1	$P = 0.02^*$	4.4	4.0	4.5	4.1	$P = 0.23$
Diet ^d (scale: 0–100%, ↑ = better)	72.9 (19.3)	72.2 (15.1)	76.6 (12.6)	69.5 (16.6)	$P = 0.19$	71.6 (18.2)	69.6 (15.5)	76.5 (12.2)	68.0 (17.8)	$P = 0.20$
Exercise ^d (scale: 0–100%, ↑ = better)	48.8 (31.6)	46.5 (21.4)	55.9 (25.0)	45.6 (22.4)	$P = 0.11$	50.8 (25.5)	48.8 (31.6)	62.5 (25.3)	55.9 (25.0)	$P = 0.26$
Self-monitoring ^d (% blood testing, ↑ = better)	44	47	52	50	$P = 0.21$	67	47	92	63	$P = 0.002^*$

Values are means (SD) except for treatment effectiveness which uses the median values and self-monitoring which uses percentage blood testing.

^a $P < 0.05$ taken as significant effect, denoted by an asterisk.

^bMeasured using Diabetes Integration Questionnaire (Welch *et al.*, 1994).

^cMeasured using Personal Models of Diabetes Questionnaire (Glasgow *et al.*, 1995, 1996).

^dMeasured using Summary of Diabetes Self-Care Activities Questionnaire (Toobert and Glasgow, 1994).

the research topic because they had all experienced the same educational intervention. Using such established groups within settings they had grown accustomed to over the 8-week intervention was felt to add to the naturalness of the discussion. In this way, there was a match between the researcher's and the participant's topic of ordinary conversation.

The focus group method was selected in recognition that group processes can help people to explore and clarify their views in ways that would be less easily accessible in one-to-one interviews (Morgan and Krueger, 1993). Kitzinger believes that they can be used to examine not only what people think, but how they think and why they think that way (Kitzinger, 1995). Stewart and Shamdasani suggest that focus groups can provide data that is rich in human experience reflecting the real-life experiences of the group members (Stewart and Shamdasani, 1990). It is essentially, therefore, a method that is adept at discovering what Bulmer describes as 'the social reality of subjects' (Bulmer, 1998). This linked into one of the aims of the trial which was to understand how intervention had influenced outcomes in the context of participants' everyday lives.

The contents of the discussions were examined and the meanings and relevant implications for the research questions explored. All the interviews were tape recorded (with informants' permission) and transcribed verbatim. A rigorous model, as described by Miles and Huberman, was used to assist in analysing the data and to lend credibility to the findings (Miles and Huberman, 1994). The constant comparative method was used to develop categories and meanings (Glaser and Strauss, 1967). These were then tested and modified through addition cycles of data collection, analysis and systematic search for negative cases (Denzin, 1994). Source, method and theoretical triangulation were used to improve the quality of the research, and confirm the conclusions induced from the data. In addition, all coding and analysis was triangulated with another member of the research team, thus incorporating a variety of theoretical standpoints and possible alternative explanations.

Qualitative results and discussion

The qualitative data was used to help explain the processes underpinning the quantitative outcomes. Two categories and their related themes were developed from questions pertaining to patients' perceptions of what they valued about the intervention. These are summarized in Table VI. The findings are presented within the context of the discussion—quotation marks and displayed quotations are used to highlight the patients' voices.

Category 1: Appropriateness of the intervention for people who have Type 2 diabetes

The course supplied 'missing' information for participants, and also improved understanding of their disease and its management. One participant described the course as an 'eye-opener', whilst another said, 'I've learnt more in the first hour here than I've learnt in nearly 5 years'. The course provided participants with the details of managing their disease within the context of their everyday lives, with frequent references to learning about 'individual' and 'small things'. One participant compared the course to reading a leaflet and stated that it had led to a better understanding because 'it sinks in better'. The groups were asked what had made the information 'sink in better' and four themes emerged.

Theme 1: Nurse's expertise and tutoring skills

The approach adopted by the nurse tutors was important to participants and was integral to the success of the course. They all spoke highly of the course tutors who appeared to attain good rapport with them through their personal commitment, empathy and interest in each person. Participants used the words 'wonderful', 'approachable', 'brilliant', 'patient' and 'knowledgeable' to describe the tutors. They also talked about the tutors showing integrity, respect and compassion toward them, as well as demonstrating their nursing expertise in diabetes:

Table VI. *Patients' perceptions of what they valued: categories and themes determined from the focus group discussions*

Categories	Themes
1 Appropriateness of the intervention for people who have Type 2 diabetes	<ul style="list-style-type: none"> ● nurse's expertise and tutoring skills ● negotiated curriculum ● experiential learning ● group support and collaborative learning
2 Timeliness following diagnosis	<ul style="list-style-type: none"> ● differential uptake of education ● aligning patients' needs to match interventions

Participant 1

They are interested in what they are doing. This is the whole thing, it's their interest in it and the way they put things over to you. Nothing is a bother to them.

Participant 2

You just felt that they were interested in you. You are not a number, you are a person.

These qualities have been identified as important to the facilitation of adult learning programmes and link into the humanist theories of learning. They reflect the nature of patient education as a process of human and moral interaction. Thorne *et al.* showed that within health care relationships these constructs were of critical importance to quality of life for people with chronic illness (Thorne *et al.*, 2000).

Theme 2: Negotiated curriculum

Participants spoke of being able to negotiate the content of the sessions with the tutors. This implied that they actively listened to them and integrated what they wanted to know into the curriculum. In this way group ownership for the courses was developed. This meant that it was effectively driven by the participants who derived a sense of individuality about the courses despite its group setting:

We could just butt in if we wanted to and ask questions and they'd stop were they were and explain it all to you and not say 'oh we'll have to cover that another day', sort of thing. There and then everything that they spoke about they went into it in real detail.

Such findings adhere to the principles of adult education which show that significant learning is more likely to take place when the subject matter is relevant to the personal interests of learners (Rogers, 1986).

Theme 3: Experiential learning

The course sought to integrate participants' personal experiences into the educational process so that learning was based upon the sharing of knowledge, attitudes and skills. This method of learning was favoured by participants who felt that it acknowledged the expertise that they had developed from living with diabetes. It affirmed their beliefs that besides formal learning there is an even greater amount of learning that can result from everyday experiences.

Many participants viewed improving disease management through lifestyle behaviour change as a 'compromise' between what had been recommended and what they perceived to be manageable on an individual level. Achieving a balance in their lifestyles was seen as being very important to the participants:

...everything can't be perfect all the time, they do not know what's going on in your life that can upset things.

Current views on self-management involve ensuring that the person with diabetes not only has access to sufficient information, skills and resources, but also feels confident in questioning the value of these (Audit Commission Report, 2000). This demands partnership between patients and health professionals in their approach to health

care because, as one participant stated, 'the patient needs expertise as soon as possible'. Participants felt that they had developed this expertise over the trial period but began to realize that health professionals do not always possess specialist relevant knowledge. This reversed the usual patient/health professional pattern of communication:

Our doctor doesn't know much about it [diabetes], neither does our practice nurse. We told her about the effect of blood pressure on diabetes, she wasn't aware of the serious connections with high blood pressure and diabetes...

Findings from the focus groups also indicated that whilst education can empower patients, not all health professionals are ready to cope with such changes and that counterproductive attitudes remain conspicuous:

Participant 1

I remember last time I saw him [doctor] for my early assessment he said 'how are you', I said 'fine', he said 'you hope', that was his words to me, 'you hope'! He said, 'I am the doctor you are the patient', so I didn't bother.

Participant 2

Well, when I was told I was diabetic at the hospital I was just told I was diabetic end of story. Nobody gave me any help or anything...after I came here I learnt a lot more about it whereas before I was just told I was diabetic, test your water and given tablets and that was it.

Atkinson notes that medical expertise is developed not simply through the possession of relevant knowledge, but is based on experiential learning in the clinical setting (Atkinson, 1981). It is this expertise which underpins the professional nature of medicine. The power relations between patients and health professionals are therefore challenged when patients also develop relevant knowledge, which together with their experiential learning, compromise their usual passive role. During the focus groups, many spoke about actively

participating with health care professionals during consultations, demonstrating confidence and self-efficacy with regard to their knowledge and understanding of diabetes. This was particularly apparent when patients were asked about their self-monitoring practices. They spoke of self-monitoring allowing them to 'see', and thus learn how their metabolism deals with such things as variations in meals and activities, and to recognize the need for modifications in treatment, including drug treatments. However, participants were not provided with information about drug self-modification. Rather, they were directed to seek advice from health professionals where they found specialist knowledge to be inconsistent and reactions to their approaches not always positive. This appeared to act as a barrier to effective self-management and was illustrated by a lack of change in drug treatments over the trial period. Proportionally more people (46%) in the trial group had had their diabetes drug treatment changed compared to the control group (30%), but these differences were not statistically significantly different (χ^2 , $P = 0.16$). In addition, 19 participants (21%) were on maximum combined oral hypoglycaemic therapy (metformin and sulphonylurea) at the start of the trial. A second drug tends to be added when secondary failure with another agent occurs, but when this happens insulin injections are usually required (Groop, 1997). Only four people in the study (two in the trial group and two in the control group) were changed onto insulin therapy during the course of the trial.

These findings have been reinforced by an audit of data on 1000 patients with Type 2 diabetes in Liverpool. Results showed that many patients were not being treated with oral agents early enough and that those treated with oral agents were not receiving adequate adjustments to their therapy to improve control (Woodward *et al.*, 2001). Such findings have highlighted the need for an organizational culture that can develop both patient and professional expertise, and allow patients to be actively involved in their care. They have been reinforced by other researchers (Kinmouth *et al.*, 1998; Rayman and Ellison, 1998; Thorne *et al.*,

2000; Paterson, 2001) and have now been translated into Government policy (Department of Health, 2001a,b).

Theme 4: Group support and collaborative learning

The group experiences played a significant part in the success of each course and were frequently mentioned during discussions. Working in groups provided participants with an environment conducive to social learning and it generated emotional experiences. The key to successful group working appeared to relate to a feeling of group empathy in which experiences and feelings about having diabetes were shared. One participant described the course as being 'between equals', implying that having diabetes had bonded them together. This appeared to encourage them to 'talk more' and, as one participant said, 'It's nice to be with people who do understand what you are talking about'.

The group format of the course therefore provided participants with opportunities to explore their attitudes toward diabetes and its treatment. It encouraged them to analyse motives for their current behaviour and provided opportunities for them to learn new skills in relation to self-managing their diabetes. Belonging to a group of people who were perceived as understanding and accepting created a feeling of cohesiveness which contributed to such learning. The tutors contributed by promoting the group processes so that it became an integral part of the educational intervention. In this way the group itself became an effective agent of change:

I've learnt about other people's ideas, other people's problems and you find that you are not on your own. You can learn how they are overcoming the problems.

The value of such collaborative learning highlighted the inadequacies of the traditional biomedical approach to diabetes care which participants described as alien to their needs. As one participant succinctly said: '...and it's like it's you isn't it, you are the physiology of it'. The main 'modus

operandi' of health education should be one of enabling, not coercing, with a focus on co-operation rather than on compliance (Tones, 1997). Participants perceived that this approach had been adopted during the courses and validated it as an empowering experience:

I am able to bend more now. I no longer find it (diabetes) a nuisance.

Category 2: Timeliness following diagnosis

Many participants spoke about the course providing the right conditions for 'pressurizing' them to take more notice of their health and commented that, 'the protected time for learning is very important'. This time was important not just for them but also for the tutors who could then devote time to patient education. In relation to this, there were feelings that the course had provided 'value-for-money' in terms of the personal time committed to attending the course. The groups were asked what had encouraged them to take part in the trial and two themes emerged.

Theme 1: Differential uptake of education

The importance of facilitating development of enduring attitudes about diabetes and its treatment suggest that intervention would be best suited to patients in the early stages of their diagnosis. This hypothesis was supported by participants, many of whom felt angry that they had not received this type of instruction much earlier in their diagnosis:

You come in, they say 'oh you've got diabetes, you've got to take this, bye bye', and you are left on your own. And you are running round like your tails been cut off thinking 'what am I going to do?'

However, it should be noted that uptake of the intervention was low, illustrating the subordinate place that education has amongst patients with Type 2 diabetes. This may reflect a culture that has perceived Type 2 diabetes to be the 'mild' form of the disease despite its association with high morbidity and mortality rates (Audit Commission Report, 2000). This perception changed for parti-

cipants during the course, reinforcing the need for earlier intervention following diagnosis because, as one participant said, 'I didn't realize that diabetes was as serious as this. It's made me realize the importance of following the diet and so on'.

Theme 2: Aligning patients' needs to match interventions

Attrition rates for the trial were low (12%, $n = 11$), but it was found that significantly more people who lived alone in the trial group remained with the trial compared to those in the control groups. As long ago as 1963, educational researchers found that loneliness was an influencing factor affecting uptake of adult education (Houle, 1963). This alludes to the fact that the reasons people attend education courses may be quite different to those that health professionals anticipate and reinforces the need to critically review factors affecting uptake.

Past research into patient education found a negative correlation between age and outcomes (Brown, 1992, 1996). This demonstrates that educational interventions need to be designed so that the plan suits the needs of those it is being designed for. It also adds to the body of evidence that the intervention used in this trial was well received by those participants who chose to participate (mean age 58 years, 42% unemployed and 27% retired), with 74% attending six or more of the course sessions, and only 15% attending less than half of the eight sessions.

Discussion: suggestions for intervention

This paper has described how theory was used to produce a framework for directing patient education and its evaluation. The strength of the study design lay in the fact that there was considerable overlap between the two data sets. This meant that there was less probability of drawing erroneous conclusions and served to validate the findings from each method. The implication of this was that the many hypotheses being tested were not independent of each other and that a relationship existed between them.

A limitation of the trial related to the number of people who agreed to take part in the study. Recruitment demonstrated that patients differed in their willingness to be educated, so how typical the trial participants were in terms of the overall population of patients could best be understood by studying those who refused to take part. Characteristics relating to age, ethnicity and sex ratio showed no differences. However, more detailed data was not available and, as such, is a limitation to generalizing the results of this study. It also implies the need for further research into the reasons why people choose to engage (or not) in educational initiatives. For those who did choose to take part, it can only be presumed that they wanted a different kind of management for their diabetes. This has implications for the results of the study because it suggests that some or all of the participants were ready to make changes. However, by using a randomized controlled trial design, which achieves comparability by equating the average unit within each of the groups and by showing that there were no significant differences between the groups' pre-test characteristics, this limitation was minimized and threats to internal validity ruled out (Cook and Campbell, 1979).

From the results of this trial a number of generalizable points can therefore be drawn.

Firstly, this study focused on participants' perceptions of what they found helpful. They described how the constructs of respect, trust, empathy and expertise were of critical importance to them, as were learning from others who have the same disease. Living with a chronic disease creates a special set of circumstances within which interactions between patients, and between patients and health professionals, appear to be critical to achieving quality of life for people. The findings from this study therefore reinforce the value of group education based on the principles of adult experiential learning and highlight the need for practitioners to look more closely at their relationships with patients. Using a theoretically constructed intervention made it possible to focus on the intrinsic communication variables that patients perceived helped them to achieve their desired

Table VII. Summary of what patients valued about the educational intervention

Salient aspects
Protected time for learning
Protected time for nurses to provide education
Augmentation of prior knowledge: new information and experiences integrated with existing knowledge and experiences
Reflection: time for reappraisal to clarify and interpret the complexities of diabetes self-management
Collaborative approach to learning between patient and tutor with personal experience likened to expertise
Tutors' expertise, empathy and personal commitment to the educational process
Learner-centred approach using principles of adult education
Supportive environment created by the group approach to learning
Shared empathy for difficulties encountered when living with diabetes in the 'real world'
Increased motivation by learning from peers

outcomes. These are summarized in Table VII and provide guidelines for intervention. They show that issues of communication and identity are central to explanations of their experiences and how patients cope with the management of their disease (Radley, 1994). To expand these findings, future studies need to focus on health care professionals' perceptions of patient empowerment and its impact upon their delivery of patient care.

Secondly, the intervention produced positive clinical outcomes over the short-term period, but these effects declined longitudinally. Findings from the focus groups suggest that reasons for this result related to lack of specialist knowledge amongst health professionals, and to a health care system that limits participants' personal responsibility and a sense of control over their fate. This reinforces the need to refocus such a model of practice as it is counterproductive to the concept of patient self-care. Governmental policy is encouraging such developments in relation to continuing professional education and developing patient expertise, but what people do about their health is largely up to them: it is their decision whether to seek help, whether to continue seeking advice and whether to comply with a treatment regime. Low uptake

of patient education reflects a cultural perspective whereby developing expertise is not yet valued and highlights the need for a paradigm shift for all, including patients.

Thirdly, low uptake of patient education may not just reflect a cultural climate that promotes dependency, it may also reflect patients' desires to continue with their passive role. Research has shown that older patients prefer to defer decision making to the professionals, but the reasons for this are not yet fully understood (Charles *et al.*, 1998). This suggests the need for further research to explore patients' perceptions of partnership in health care. This may then provide guidelines about who to target for patient education.

It suggests that health care professionals have brought into the empowerment model of health care without accepting its underlying goals. This implies misconception about what shared decision making in health care involves (Playle and Keeley, 1998). The government's agenda is to develop patient expertise, and within this there is great emphasis upon health professionals working in partnerships with patients and involving them in decision making about their own treatment and self-care (Department of Health, 2001a). These goals are presented as compatible and their mutual implementation is presumed to lead to a 'first class service' (Department of Health, 1998). The findings from this study suggest potential for conflict given the different levels of expertise amongst both patients and professionals working in primary care. This has highlighted the need for health professionals to become aware that care for chronic illness is an inherently different social enterprise than is care for acute illness. Such tensions argue for the integration of medical and social sciences into professional education at all levels so that they work in concert with each other. It has therefore shown that the long-term aims of patient education cannot be achieved without corresponding professional education. With the focus on developing 'expert patients', alongside the rising prevalence of Type 2 diabetes, this need has become even more urgent.

Conclusion

Whilst education can empower patients to take on greater responsibility for the management of their disease, they cannot achieve long-term success without the cooperation of health professionals who can support and facilitate achievement of patients' goals. This role demands a greater understanding of the theories underlying patient education and the communication skills required to promote such autonomy. This reinforces the argument for integration of medical and social sciences into professional education so that partnerships with patients can be realized. Within this philosophy, responsibility for management of the disease resides with patients and the primary role of the health professional becomes one of supporter and educator. Failure to afford systematic attention to the significance of these factors continues to reinforce the passive role of patients so that the burden of coping with chronic illnesses like diabetes is reinforced at both individual and community levels.

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